‘Till Long-Term Care Do We Part’: Exploring the Impacts of Separating Married Couples on Couplehood and Well-being

by

Lindsay Grasso

BA, University of Victoria, 2018

Project Submitted in Partial Fulfillment of the
Requirements for the Degree of
Master of Arts

in the
Department of Gerontology
Faculty of Arts and Social Sciences

SIMON FRASER UNIVERSITY
Summer 2021

Declaration of Committee

Name:	**Lindsay Grasso**
Degree:	**Master of Arts**
Title:	**'Till Long-Term Care Do We Part': Exploring the Impacts of Separating Married Couples on Couplehood and Well-being**
Committee:	**Chair: Atiya Mahmood** Associate Professor, Gerontology
	Barbara Mitchell Supervisor Professor, Gerontology
	Habib Chaudhury Committee Member Professor, Gerontology
	Laura Funk Examiner Professor, Sociology University of Manitoba

Abstract

This capstone project explores the impact of separating married couples when one spouse has dementia in long-term care settings. In particular, on couples' abilities to maintain a sense of couplehood within the socio-physical environment of long-term care and its impacts on each spouse's health and wellbeing. The theoretical perspectives of attachment theory and person-environment exchange are utilized to guide this project, providing a holistic and insightful approach to investigating spousal relationships in long-term care. The goals of this project are two-fold. First, a scoping review of the limited literature will be presented. Second, based on the Canadian Institute of Health Research (CIHR) Project Grant guidelines, a mock grant proposal was developed. The purpose of the grant is to critically examine the institutional practice of separating married couples in LTC settings in British Columbia when one spouse lives with dementia and requires more complex care and support. The proposed study will focus on couples' abilities and challenges in maintaining their relationship within the LTC environment and the effects of separation on their health and wellbeing. Overall, this capstone project will help guide future research, practice, and policy in this important yet understudied topic in gerontology.

Keywords: Long-term care; Older couples; Separation; Marital relationship; Couplehood

Dedication

I dedicate this Capstone Project to the memory of my great aunt and uncle Shirlè Klein-Carsh and Fred Carsh, whose lived experience inspired this project.

Acknowledgements

First, I would like to thank my supervisor, Dr. Barbara Mitchell. I am incredibly grateful for your continuous support and guidance throughout my time in the program and in the completion of this capstone project. Your words of encouragement have meant so much to me. I would also like to thank my committee member, Dr. Habib Chaudhury, for his instrumental insight, feedback, and ongoing support.

I also want to thank Dr. Laura Funk, my external examiner, for contributing her time and expertise to my project. I want to express my sincere thanks to Leah Deslauriers and Lisa Cohen Quay, as well as my L’Chaim Adult Day Centre family, for their mentorship, friendship, and unwavering support. The opportunities you both have provided me are invaluable to growing my passion and confidence in the field of gerontology. Additionally, I want to thank Jasjit Gill and my colleagues from my internship with the then Dementia CARE Initiative at Vancouver Coastal Health for believing me and inspiring me to be the change I want to see.

Finally, I would like to thank my friends and family for all their love and support. I would especially like to thank my mother, Bonnie Grasso, who I am grateful for every day and who has always been a source of inspiration and support. Also, my late father Tony Grasso and late Bubbie Mary Powell whose memory and words of support I take with me in everything I do. I would not be who I am today without the three of you.

Table of Contents

List of Acronyms

A-B	Agency and belonging
AL	Assisted living
BC	British Columbia
CIHR	Canadian Institutes of Health Research
ETA	Ecological theory of ageing
FHA	Fraser Health Authority
IL	Independent living
LTC	Long-term care
P-E	Person environment
VCH	Vancouver Coastal Health

Chapter 1.

Introduction

1.1. Background and Rationale

Canada's changing demographics, as a result of population ageing and increased longevity, means that more married couples than ever before will live to share the experience of old age (Kemp, 2008; Milan et al., 2014). It is estimated that more older couples will experience a caregiving relationship in which one spouse faces health declines, such as living with dementia (Hellström et al., 2005; Milan et al., 2014). The Alzheimer's Society of Canada reported that as of 2018, "over half a million Canadians are living with dementia… [and that] by 2031, the number is expected to rise to 937,000, an increase of 66 percent" (Alzheimer's Society of Canada, 2018). Recent estimates in Canada also show that 46% caregivers to persons with dementia are spouses and that 99% of them live in the same household with 97% providing daily care (Wong et al., 2016).

Spousal caregivers are well known to experience a multitude of both positive and negative emotional and physical health consequences due to caregiving (e.g., depression and anxiety). Deleterious consequences for the coupled relationship can be especially pronounced as a result of the progression of dementia (Arbel et al., 2019; Evans & Lee, 2014). These impacts of facing dementia in the spousal relationship are well-recognized in research (Førsund & Ytrehus, 2018; Mullin et al., 2011). Given the progressive nature of the disease, it is understood that for spousal caregivers, their partners' deterioration of cognitive abilities can lead to several emotional losses (Evans & Lee, 2014; Hellström et al., 2005). For example, the condition of dementia affects spouses' "familiar means of communicating and interacting with their partners and their ability to maintain mutual support and connection" (Førsund & Ytrehus, 2018, p. 1; Hellström et al., 2005). Despite these losses, research reveals that many spouses can maintain their desired relationship quality and that caregiving can further strengthen their relationship (Førsund & Ytrehus, 2018; Mullin et al., 2011). Notably, research has shown that spouses “shared health habits (such as diet and exercise) and life circumstances (such as access to medical care)” can result in synchronous health declines between spouses (Kemp, 2008; Schulz & Sherwood, 2008, p. 5). The progressive nature of dementia can often lead to increasingly demanding caregiving responsibilities, which can be taxing on ageing spousal caregivers who may be facing health challenges of their own (Brownie et al., 2014; Kemp, 2008; Wong et al., 2016). These circumstances can challenge a couple's ability to live independently in their homes, consequently triggering their collective relocation into long-term care (LTC) settings (Brownie et al., 2014; Kemp, 2008; Wong et al., 2016).

As of 2016, it has been reported that 9.2% of women and 4.9% of men aged 65 years and older live with a spouse in a primary health care and related facilities, such as LTC settings (Statistics Canada, 2017; Wister, 2019). These numbers increase to 35.6% of women and 23.1% of men for older adults aged 85+ (Statistics Canada, 2017; Wister, 2019). Although couples are currently a minority in LTC settings, researchers predict an increase in the commonality of married couples living together in LTC due to increased longevity and the likelihood of age-related health declines and disability (Gladstone, 1992; Milan et al., 2014). Research reveals that couples' collective relocation experiences to LTC are linked to their strong aspirations and marital commitments to stay together (Kemp, 2008, 2012). It is observed that although "relocation was motivated primarily for the needs of one spouse, both partners were compliant in the decision to move, in part because they wanted to be together" (Kemp, 2008, p. 214). However, current institutional practices in British Columbia (B.C.) Canada invokes the separation of married couples in LTC settings, such as having one spouse reside with more complex care needs reside in LTC, while the other in assisted living (AL) or independent living (IL). This common practice highlights the importance of understanding the features and significance of couplehood, defined as "the relationship between two committed individuals, characterized by a sense of…shared identity, a sense of purpose, and commitment" in the LTC environment (Kaplan, 2001; McGovern, 2012, p. 5).

Although research on this topic is sparse, the separation of married couples in LTC settings when different care needs are required has received significant media attention in recent years. For example, a report in The Globe and Mail (2016) emphasized the severe toll forced separation had on a couple who were placed in different facilities due to one spouse having advanced dementia. Ultimately, the physical separation significantly affected both spouses stating that each has suffered a decline in both physical and emotional health status (Kane, 2016). Furthermore, the current

COVID-19 pandemic has brought the challenges and importance of maintaining familial connections to the forefront. In March of 2020, the Provincial Health Officer Dr. Bonnie Henry invoked residents' movement restrictions within and between LTC settings, allowing only those deemed 'essential visitors' (Seniors Advocate of B.C., 2020).

During this pandemic time, married couples unable to visit each other gained much attention in the media, often drawing parallels to being separated across oceans during war times (e.g., Grant, 2020). For example, in June 2020, CBC News reported that a couple already separated within different LTC settings in the Kootenay region have been unable to reunite with each other in person due to the pandemic (Migdal, 2020). Although staff members at each home have facilitated phone and video calls for the couple to connect, the news article expressed that each spouse was "exceptionally depressed" with phone and video calls often ending in tears (Migdal, 2020, para. 20). Moreover, due to isolation and inability to see/speak to one another in person, their relationship quality had deteriorated, and one spouse's health has rapidly declined (Migdal, 2020, para. 20). This indicates that for the couples already involuntarily separated between and within different LTC settings, the pandemic visitor restrictions profoundly intensified the emotional impacts caused by their separation.

Effective as of June 28, 2020, the visitor restrictions policies were revisited, and all residents in LTC settings (LTC, AL, and IL) are currently allowed to have one designated ‘social visitor’ that can include a family member or friend (Office of the Seniors Advocate of British Columbia [B.C]., 2020). A recent investigative report from the Office of the Seniors Advocate of B.C. on the impact of visitor restrictions in LTC found that for spouses in particular, the compounding nature of separation in the prior months, their spouses declining health, and the current visiting experience and infection control practices, have considerably impacted their overall well-being and arguably their desired relationship quality. To illustrate, the results of their survey, which was taken on August 26, 2020, till September 30, 2020, found that 72% of spouses who visit their partner (majority with dementia) reported that they are not allowed to physically touch their partner, including holding their hand or hug them (Office of the Seniors Advocate of B.C., 2020). In addition, visits are supervised by care home staff, at times timed, and visitors are not permitted in their loved one’s rooms (Office of the Seniors Advocate of B.C., 2020).

Concerns about the mental health impacts of isolation and visitor restrictions on residents in LTC settings, especially persons with dementia, have been noted as a significant issue throughout the course of the pandemic. The survey found that in addition to the frustrations and heartbreak expressed by spousal caregivers, for persons with dementia, the prolonged separation from ones loved one has increased the rate of antipsychotic medication use by 7% (Office of the Seniors Advocate of B.C., 2020). The COVID-19 pandemic has reinforced the integral role connections with loved ones have on residents' health and well-being. The significant impact of the pandemic on residents in LTC, specifically, couples' ability to interact and maintain their relationship, draws parallels to couples' frustrations and experiences with involuntary separation in LTC as a result of different care needs.

The experiences of couples when one spouse has dementia is often portrayed in the literature as a life of loss, frustration, burden, and stress (Swall et al., 2019). Moreover, the relationship experiences and impacts on health are typically from the spousal caregivers' sole perspective (Bielsten & Hellström, 2019). However, being a spouse and caregiving for a person with dementia "is not a uniformly negative experience," with many spousal caregivers expressing positivity and satisfaction in their role (Førsund et al., 2015, p. 122). In effect, there is a clear gap in research concerning a couple's sense of unity within their everyday lives and how that transposes into providing care and the marital relationship when one spouse has dementia (Swall et al., 2019). In a similar vein, research on the lived experiences of persons living with dementia in marital relationships, their feelings of necessity to maintain their relationship in LTC, and the potential implications of marital relationships in their care and quality of life are largely overlooked. Accordingly, research to better understand older couples' experiences and lives living in LTC settings is essential to promote successful, supportive interventions and inform policy and practice.

The B.C. Ministry of Health recognizes the significance of relationships among older couples in LTC settings and developed a provincial policy that aims to ensure the "continuity of spousal relationships when only one spouse requires [LTC] services" (British Columbia Ministry of Health, 2019, sec. 6.D.1). The policy obliges homes to establish reasonable arrangements for spouses to live in the same home or nearby accommodation (e.g., AL/IL) to maintain contact and relationship (British Columbia Ministry of Health, 2019). Like other provinces such as Halifax, Nova Scotia, and Ontario who have passed legislation in 2020- 2021, the policy ensures that couples can remain together in LTC despite different care needs. However, as the policy details are fairly recent, the practical implications of couples' accommodation are uncertain (e.g., how individual LTC settings have executed this policy, how often the qualifying couple may be able to live in the same care home, and the specifications when one spouse is living with dementia). Also, the COVID-19 pandemic presumably has impacted the implementation of the policy. As a result, it's unknown whether LTC homes have implemented this policy since enacted, or whether the pandemic will have an impact on its future use. Given the regulation's ambiguity and novelty, the Canadian Institute of Health Research (CIHR) grant application and proposed study will aim to address our knowledge gaps in this area. The proposed study will be further described in a later chapter.

1.2. Definitions of Key Terms

The key terms used in this capstone project and CIHR Grant Proposal need to be defined. The term dementia is used as an umbrella term to refer to people diagnosed with Alzheimer's disease, vascular dementia, Lewy-Body disease, frontotemporal dementia, and dementia of the 'mixed' type (Alzheimer Society of Canada, 2020). LTC settings are defined as age care settings that provide "a variety of services designed to meet a person's health or personal care needs during a short or long period of time. These services help people live as independently and safely as possible when they can no longer perform everyday activities on their own" (National Institute on Ageing, 2019, sec. What is Long-Term Care?). LTC services offer persons with complex care needs who cannot be safely cared for in their own homes or an assisted living facility with round-the-clock professional care (Government of British Columbia, 2020). Persons with dementia who require LTC in B.C. may be relocated to various settings, including an LTC home and specialized dementia care units within an LTC home or AL facility.

Lastly, the term marriage is defined in accordance with the Family Law Act of B.C., which defines a spouse as “is married to another person or has lived with another person in a marriage-like relationship and has done so for a continuous period of a least 2 years” (Family Law Act, SBC 2011. c 25, s.1 (3)). Notably, within this act, both common-law relationships and non-heterosexual relationships (LGBTQ+) are recognized. Thus, spousal relationships are identified as an ongoing relationship between two individuals, rather than solely through legal means of relation (Førsund, 2017). Although there is diversity in meanings and definitions of marriage across research studies, for the purpose of this project, it will be recognized as a long-standing spousal relationship in which partners share emotional, financial, and social attachment for an extended period (Braithwaite, 2002; Hunt, 2015; Walker & Luszcz, 2009).

1.3. Characterizing Shared Identity and Couplehood

Marriage is considered to be the most influential social relationship that affects an individual's life and well-being (Hunt, 2015; Wagner et al., 2018; Walker & Luszcz, 2009). It encourages commitment, reciprocity in partnership, and the shared meaning of experiences between two individuals (Wagner et al., 2018). Marriage in long-term couples "is unique as the spouses are usually very close…hav[ing] mutually experienced and managed conflicts, setting the same goals, and obtaining a deeper emotional meaning within their relationship" (Hunt, 2015, p. 36). Long-term marriage and shared experiences can result in the sense of mutual identity (Braithwaite, 2002; Førsund, 2017). Couples' shared identity (also known as relational identity) is described in the literature as "an expression of their experience of togetherness… [and] as a sense of "we-ness" manifestat[ed] of their mutual understanding of the value of their existing relationship" (Førsund, 2017, p. 8; Rogers-De Jong & Strong, 2014). Within this context, the importance of the marital relationship for older couples is further affected by their decrease in social networks (e.g., death of close friends and family), as well as a spouses' deterioration of health status (e.g., mobility and presence of chronic illness) (Braithwaite, 2002). In turn, older spouses typically develop an intense bond as they become increasingly dependent on one another for care and companionship (Hunt, 2015).

In consideration of the interdependence of older couples' and the significance of their spousal relationship, "couplehood" has emerged as an important concept in dementia literature (Evans & Lee, 2014). First described by a Hellstrom et al. (2005), a case study that highlighted the relationship and experiences of an older married couple where one spouse has dementia, couplehood was used to emphasize their desire to 'maintain involvement' and continue their relationship (Hellström et al., 2005). The authors suggest that stemming from the definition of personhood described by Kitwood (1997) "that couples affected by dementia should be viewed as a unit rather than two separate individuals" (Swall et al., 2019, p. 2). It has been found, that despite the multitude of emotional losses associated with dementia, spouses are able to maintain the quality of their relationship and a strong sense of commitment to their partner (Hellström et al., 2005, 2007). As Wadham et al.'s (2015) literature review of couples' mutual experiences of dementia describes/concludes, couples affected by dementia "view dementia as a shared experience," impacting not only their individual lives, but the mutual experience of their relationship (p. 10). Viewing dementia as a socially co-constructed experience rather than solely affecting one partner demonstrates the significance of preserving spousal caregivers' pre-existing identity within their marriage as a spouse to their partner, and the power within a couple's mutual sense of identity (Funk, 2019). This conceptualization further enables "couples to ally against the dementia, empowering them to collaborate and face the difficulties together as a united front" (Wadham et al., 2015, p. 10). This finding relates to Hernandez et al., (2019) study of couples' shared sense of identity in dementia found that the decades of shared experiences and closeness have reinforced their shared identity and created a powerful bond that is resilient to challenges. Couples with a strong sense of couplehood have been described to experience friendship, reciprocity in partnership, trust, and intimacy (Førsund, 2017; Kaplan, 2001; Wadham et al., 2015).

Kaplan (2001) developed a typology of marital relationships when one spouse has dementia and resides in LTC, exploring the concept of couplehood, defined as "the extent to which [spouses of persons with dementia] perceives oneself as married (feelings of belonging to a "We" [as opposed to] feeling like an "I") (p. 87). Kaplan (2001) demonstrated a wide range of perceptions of couplehood with five distinct categories (1) "Till death do us parts", (2) "We, but…," (3) "Husbandless wives/wifeless husbands," (4) "Becoming an I," and (5) "Unmarried marrieds" (Kaplan, 2001, p. 87). Kaplan argued that the categories are dependent on both a couple's past and present experiences of their relationship and the level of change in their relationship due to the progression of a spouse's dementia (Kaplan, 2001). Swall et al. (2019) stated that in the nature of dementia progression, many obstacles challenge the sense of 'us' in their relationship; however, that the ability to continue doing things of value together, including familiar routines and shared new experiences, enables the sustainment of the sense of 'us' and fuels the strength of their relationship (Swall et al., 2019). As Føsund (2017) suggested, the way in which couples maintain a sense of couplehood is within an ongoing process of adjustment to the ever-changing situations in which persons with dementia and their spouse face when living with dementia. Viewing spousal relationships from this perspective enables a deeper understanding of the unique life experiences that define spousal relationships, which creates meaning in each spouse's daily life. Having this understanding can further aid in exploring the impacts of separation on spousal relationships and the implications of maintaining the key elements of a couple's relationship in the LTC environment (Førsund, 2017).

1.4. Purpose and Research Questions

This capstone project aims to address the current gaps in research by shedding light on the lived experiences of married couples residing in LTC, a population currently under-represented. In particular, this project aims to extend and complement prior research involving persons with dementia's perspectives and the subjective experiences of dyadic relationship well-being when one spouse has dementia. Two objectives guide this project, the first is to complete a scoping review on the limited literature on the topic at hand. The findings of the scoping review will be utilized for the identification of key themes and knowledge gaps. Second, based on the scoping review's findings, this project will develop a simulated Project Grant application based on the guidelines outlined by the Canadian Institute of Health Research (CIHR). The purpose of the CIHR grant will be to critically examine the institutional practice of separating married couples in LTC settings in B.C. when one spouse lives with dementia and requires different care and support. The proposed empirical study will examine: a) couples' abilities and challenges to maintain the quality of their relationship when separated by the policies and practices of LTC, and b) how separation and potential loss of couplehood influence both spouses' overall health and well-being. Additionally, the study will explore how the LTC's socio-physical environment, such as attitudes of care home staff and the environmental features (e.g., meal seating arrangements, distance between units) influence couples' opportunities and abilities to meaningfully interact with each other.

Although there is ample literature exploring the impacts of LTC's socio-physical environment on visiting spouses (community-dwelling) abilities to maintain their sense of couplehood, the examination of couples' challenges when both spouses reside in an LTC setting is scant. Additionally, there is a current lack of research that addresses the perceptions of both spouses (i.e., the caregiving spouse and the spouse with dementia), thus, disregarding both spouse's experiences. This omission presents a significant gap in knowledge. It neglects a core characteristic of person-centred/person-directed care practices, maintaining familial bonds and including family in care (Alzheimer's Society of British Columbia, 2011). Therefore, this research will be valuable as it will critically evaluate the procedures and culture of care that impact a couple's abilities to maintain their relationship. In particular, the proposed research will be instrumental in refining existing policies and providing evidence to move toward a more flexible model of care that supports the continuation of marital relationships. Furthermore, the study will advance our conceptual understanding of couplehood in the LTC environment. The empirical study's findings will inform the development of innovative initiatives to support a couple's emotional needs, and improve and/or sustain their overall health and quality of life in LTC settings.

Chapter 2 will describe the theoretical perspectives that will guide the CHIR grant proposal and proposed study, and chapter 3 will provide a synopsis of the existing literature. In Chapter 4, I will discuss the methodology of the scoping review and the proposed empirical study. Lastly, Chapter 5 will present the CIHR Project Grant Proposal following the Fall 2020 and Spring 2021 guidelines.

This project will be guided by two overarching research questions with five sub-questions:

- **Research Question 1:** How does the current practice of separating married couples between LTC settings (including AL and IL) when one spouse is living with dementia and resides in LTC impact the marital relationship and couples' abilities to sustain couplehood?
    - **Sub-Question:** What are the challenges couples face in maintaining couplehood?
    - **Sub-Question:** What are the mental and physical health effects both individuals may face when separated in LTC settings? (e.g., responsive behaviors in persons with dementia, depression, anxiety, malnutrition).
- **Research Question 2:** How does the LTC socio-physical environment influence couples' opportunities to maintain their relationship?
    - **Sub-Question:** What is the understanding of care home staff (e.g., nurses, care-aids, directors of care, and executives) of couples' needs in LTC?

- **Sub-Question:** What policies and care practices act as barriers in couples' capacity to maintain the desired aspects of their relationship in the LTC environment?
- **Sub-Question:** What physical environmental features of the LTC setting inhibit couples' capacities to interact meaningfully? (e.g., locked units, locks on private bedroom doors, distance between units, lack of privacy).

Chapter 2.

Theoretical Perspectives

This chapter will begin with a brief review of the conceptual and theoretical works on marital relationships relevant to this project. This discussion will be followed by an overview of the selected theoretical perspectives that will guide this capstone project, including the proposed CIHR grant proposal: attachment theory and person-environment (PE) theory. Finally, this chapter will conclude with a discussion of how the two theories work together in relation to this project.

The multidimensional role of marital relationships in later life has been widely conceptualized (e.g., Willoughby et al., 2015; Mitchell, 2016). A couple's mutual sense of identity, shared experiences, and companionship have been demonstrated to impact the experience of ageing and are recognized to have a beneficial role in each individual's health and well-being (Førsund, 2017; Hunt, 2015). As noted above, the nature of the spousal relationship when one partner is living with dementia is profoundly influenced by cognitive decline (Evans & Lee, 2014; Hernandez et al., 2019). Therefore, how couples are able to adapt to these changes will influence their interactions and sense of couplehood (Evans & Lee, 2014; Hernandez et al., 2019; Kaplan, 2001).

Various theoretical frameworks in social gerontology can be relevant in conceptualizing the interconnectedness of couples' lives and the experience of dementia within the marital relationship. For instance, several studies that focus on understanding spousal relationships when one spouse has dementia draw on the theoretical framework of symbolic interactionism (e.g., Kaplan, 2001; Førsund, 2017; Mullin et al., 2013; Førsund et al., 2015; Hunt, 2015). Symbolic interactionism emphasizes that individuals in marital relationships develop a symbolic and personal definition of marriage in which they reconstruct conceptions of their identity to be part of a unit as described by their experiences and interactions within their society's culture and social relationships (Kaplan, 2001; Willoughby et al., 2015).

Similarly, the life course perspective has also been applied to the investigation of marital relationships in later life. As Mitchell (2003) explains, the life course perspective "reflects the intersection of social and historical factors with personal biography and development within which the study of family life and social change can ensure" (p. 1051). The central concepts of linked lives and transitions have often been utilized to highlight how married couples' lives are interdependently linked and shaped by both independent and collective circumstances and experiences (Mitchell, 2003, 2016). Kemp (2008) applied the life course perspective and the concepts of linked lives and transitions to explore couples' collective trajectory to LTC. The author utilized these concepts to refer to how "married couples' relocation to and lives in [LTC] are likely to be shaped by their individual and shared cumulative life experiences" (Kemp, 2008, p. 232). For instance, marriage in later life is marked by a number of life transitions, including the loss of social networks and support (e.g., the death of friends and family members), retirement, widowhood, and changes in health status (Mitchell, 2003, 2016). Changes in a spouse's health status unquestionably affect the lives of both spouses (Kemp, 2012). Although couples may experience health declines at different times, health transitions alter the spousal relationship, as one spouse becomes dependent on the other (Kemp, 2008; Roberto et al., 2013).

Although these frameworks have merit and can offer insight into the conceptualization of couplehood and the perceived effects of involuntary separation, the perspectives of attachment theory and person-environment (PE) exchange supplement an additional understanding of the phenomenon. For example, attachment theory (Monin et al., 2013; Waldinger et al., 2015) provides a more comprehensive understanding of the more social-psychological elements of older dyadic relationships, which influence behaviour, which neither symbolic interactionism of life course perspective might emphasize to the same extent. In addition, PE exchange, in particular, Chaudhury and Oswald's (2019) integrative framework, offers a perspective that can encompass specific aspects of the LTC environment, in which symbolic interactionism and life course perspective would typically not address (e.g., physical design/layout). In consideration of these points, drawing upon attachment theory and P-E exchange offers a unique conceptual understanding. In this way I can conceptualize both the subjective experiences of emotional attachment between spouses and the influence of the LTC socio-physical environment on a couple's abilities to maintain their sense of couplehood. Concepts and principles relevant to my capstone project from each of these two theories will be discussed in detail below.

2.1. Attachment Theory

Attachment theory was developed by John Bowlby (1969) and the works of Mary Ainsworth (1989). It provides a critical understanding of the natural human desire to establish and maintain close relationships throughout the life course (Waldinger et al., 2015). Although Bowlby's attachment theory is based on infants and children attachment to parental figures, empirical research has increasingly been exploring the attachment models of marital relationships in later life (Bradley & Cafferty, 2001; Ingebretsen & Solem, 2009; Monin et al., 2013; Waldinger et al., 2015). In particular, there is a growing body of research that applies attachment behaviours to caregiving dyads in later life and the behaviours of persons with dementia in their responses to change and loss (Bradley & Cafferty, 2001; De Vries & McChrystal, 2010; Monin et al., 2013). In the same vein, attachment theory has been demonstrated to be a useful framework when investigating the subjective experiences of both persons living with dementia and their caregivers (e.g., Ingebrestien & Solman, 2009; Monin et al., 2013).

The framework enables the conceptualization of couples' reciprocity in partnership and the natural desire for individuals to "seek support from others in times of threat, such as when a person experiences dementia, and to care for others who are suffering" (Monin et al., 2013, p. 509). Applied to this study, attachment theory provides a conceptual means of understanding the relationship between a couple's enduring emotional attachment, their desires to remain together, and the health effects of their involuntary separation (Chircop, 2017; Monin et al., 2013; Waldinger et al., 2015).

In marital relationships, it is theorized that the spouse's interactions and perceptions of relationship quality can be based on *secure* or *insecure* attachment (Monin et al., 2013; Chircop, 2017, p. 16). Although other attachment styles exist, literature applying this framework to marital relationships in later life has predominately focused on these two (e.g., Chircop, 2017; Monin et al., 2013; Ingebretsen & Solem, 2009). Connected with couplehood, Chircop (2017) relates these attachment styles to couples' sense of emotional connectedness during times of stress or conflict (either adapting their relationship or becoming more disconnected), which can be directly related to a couple's sense of shared identity when elements of their relationship are challenged.

Attachment is further viewed through the development of a *secure base* in which children cultivate a natural emotional bond to an attachment figure (often a parent or parental figure) and develop adaptive system behaviours in which they actively seek to maintain proximity with their attachment figure and “protest following involuntary and perceived permanent separation” (De Vries & McChrystal, 2010, p. 288; Pittman et al., 2011). Maintaining proximity is further linked to the individuals' sense of security and safety within their physical and social environment, and particularly prominent in times of ill health (Chircop, 2017; De Vries & McChrystal, 2010; Pittman et al., 2011). For older couples, the interconnectedness of their lives often translates into spouses becoming each other’s secure base (Hernandez et al., 2019; Pittman et al., 2011). This notion is particularly relevant when one spouse transitions into a caregiver for the other, such as when one spouse is living with dementia (De Vries & McChrystal, 2010). When viewing older couples’ relationships in these terms it becomes easier to conceptualize the importance of couples remaining together and the impacts of their separation.

To illustrate, attachment behaviours can impact both spousal caregivers and the experiences and well-being of persons with dementia (Bradley & Cafferty, 2001; Monin et al., 2013). For persons with dementia, attachment behaviours influence “how they express emotions, react to family visits, and behave” (Monin et al., 2013, p. 509). De Vries and McChrystal (2010) note that new and strange environments such as LTC settings increase persons with dementia attachment behaviours. For persons with dementia, being physically separated from one’s secure base, was found to spark feelings of insecurity in their surroundings, exhibiting signs of distress and anxiety (e.g., crying, looking for their partner and responsive behaviours) (Bradley & Cafferty, 2001; De Vries & McChrystal, 2010; Monin et al., 2013). When consistently separated from their loved one, it has been found that persons with dementia “maintains that the awareness-context causes the dementia sufferer to experience a chronic trauma related to separation, loss, powerlessness, displacement and homelessness” (De Vries & McChrystal, 2010, p. 293). At the same time, caregiver's attachment behaviours are linked to the well-being of persons with dementia (Monin et al., 2013). It is suggested that spouses who share a higher sense of couplehood can become more distraught and anxious when their spouse exhibits signs of distress or pain (Monin et al., 2013). The dimension of maintaining physical proximity parallels to the exploration of the involuntary separation of married couples. The application of attachment theory to this project thus provides valuable insight into how and why physical separation can be detrimental to both spouse’s health and well-being and why the continuation of their desired relationship quality is important.

2.2. Person Environment (P-E) Exchange

Since a key component of this project and CIHR grant proposal is to investigate how the socio-physical environment of LTC settings can create challenges in couples’ ability to sustain their desired relationship quality when one spouse is living with dementia, it is essential to include the conceptual perspective of environmental gerontology. The overarching framework of the ecological theory of ageing (ETA), provides a broad understanding of the interaction between an individual's level of competence, such as cognitive functioning and physical health, and the pressure of their objective environment within the individual's abilities to adapt (Albuquerque et al., 2018; Lawton & Nahemow, 1973; Wahl et al., 2012). From this lens, it is assumed that an individual’s “optimal level of functioning” is determined by the interaction of their level of competence and the features of their physical environment (Chaudhury & Oswald, 2019; Wahl et al., 2012).

Complementing the ETA, person-environment exchange (P-E) “is a function of subjective experiences in affective and cognitive terms, personal meanings, and attachment” (Wahl et al., 2012, p. 307). The established constructs of place attachment and place identity highlight the experiential process of transforming places of insignificance into places of meaning (Rowles & Bernard, 2013). Commonly applied to an individual’s abilities to cultivate emotional connections with their home, place attachment has been utilized in empirical literature to understand residents (in particular, persons with dementia) abilities to adjust and transform the unfamiliar setting of LTC into a place of significance that can host meaningful interactions (Førsund & Ytrehus, 2018; Rowles & Bernard, 2013). Chaudhury and Oswald (2019) present an integrative approach to P-E exchange and conceptualizes P-E interactions within the interplay of four components, “individual characteristics, social factors, physical/built environment and technological systems” (p.2). Additionally, this approach highlights the interaction of *agency* and *belonging* (A-B) within the developmental outcomes of *identity* and *autonomy* (Chaudhury & Oswald, 2019). The interplay of these dynamic components can explain the complex attributes of spousal relationships and their implications within LTC settings. In association with conceptualizations of couplehood, which note that couplehood is maintained through a couples' abilities to adapt to new environments and situations as dementia progresses, Chaudhury and Oswald's (2019) P-E exchange framework enhances the understanding of the mechanisms in which couples adapt to the socio-physical environment of LTC (e.g., environmental design, culture of care, and social/care interactions with care staff, as well as other residents) and how the environment of LTC can challenge couples' abilities to maintain their desired relationship quality post-relocation (Swall et al., 2019).

Chaudhury and Oswald (2019) contextualize *agency* as illustrative of individuals' abilities to act with intent within their objective socio-physical environment and *belonging* as reflecting an individual's subjective attachment and likely integration to that environment (e.g., personalization of private bedrooms in LTC settings). The A-B relation is further "based on the function(s) or goal (s) of an interaction, e.g., independent functioning, social interaction, mobility, safety and security, continuity of self, or pleasure and joy," which intrinsically shape the concepts of *identity* and *autonomy* (p.2). Identity is formed via the construction of one's own self under the impact of one's socio-cultural surroundings (Bernard & Rowles, 2012; Funk, 2019). Identity is further connected with continuity i.e., maintaining a sense of self through activities, routines, physical appearance etc. which is inherently associated with personal well-being (Bernard & Rowles, 2012; Chaudhury & Oswald, 2019). In turn, maintaining identity is closely connected with autonomy which is characterized as an individual's ability to preserve their independence (Chaudhury & Oswald, 2019). Within the context of this capstone project, identity and autonomy play an integral role in the conceptualization of marital relationships in LTC settings (Brownie et al., 2014; Førsund, 2017; Jungers, 2010).

For each spouse, both individually and collectively, the transition to LTC can be an emotional experience that can impact an individual's perceptions of identity, safety, and autonomy (Brownie et al., 2014; Jungers, 2010, p. 417). This notion is further escalated in the context of their physical separation between care facilities and is further sanctioned with the loss of the presence of their spouse in everyday life (Førsund, 2017; Førsund et al., 2015). To illustrate, in connection with attachment theory separation from ones 'secure base' (spouse) can impact individuals' sense of safety and security within their environment (Hernandez et al., 2019; Pittman et al., 2011). Maintaining a sense of security is further correlated with one's preservation of autonomy, which can be affected by the symptoms of dementia (Chaudhury & Oswald, 2019). For persons living with dementia, the interplay of A-B dynamics is presumably intensified, as "functioning challenges associated with a decline in health would likely affect one's level of effective agency to decrease along with a parallel increase in the value of the affective aspects of belonging" (Chaudhury & Oswald, 2019, p. 4). Therefore, this framework can provide an understanding of the socio-physical environmental impact of LTC on persons with dementia within the nuanced context of marital relationships and the impacts of separation from their partner.

Utilizing Chaudhury and Oswald's (2019) P-E exchange perspective affords a useful framework to critically evaluate the socio-physical environment of LTC settings and its impact on separated dyads in LTC settings when one spouse lives with dementia. The framework can aid in the conceptualization of how couples are able to adapt to their new environment and create a place of meaning that represents their shared identity and relationship within the socio-physical environmental features of LTC that challenge this arguably vital process in the sustainment of couplehood. For example, agency and belonging are demonstrated within a couple's ability to preserve shared routines and continue the development of shared experiences, which is seen as a vital component of maintaining couplehood (Chaudhury & Oswald, 2019; Førsund & Ytrehus, 2018; Førsund, 2017; Mullin et al., 2011). This lens further enhances the argument that couples' abilities to maintain their desired relationship quality with their spouse (i.e., perform familiar routines, share meals and activities, and maintain desired proximity to each other) is an essential aspect in each spouse's maintenance of agency and establishment of belonging in LTC settings.

The two theoretical perspectives presented in this chapter, attachment theory and P-E exchange, collectively offer useful insight into the critical evaluation of LTC's socio-physical environment influences on the continuity of marital relationships when one partner has dementia. As demonstrated above, attachment theory presents a valuable framework to understand the dimensions and significance of the enduring emotional attachment of older couples, enhancing our comprehension of couplehood. In addition, providing a conceptual means for comprehending the value of remaining together and the perceived health consequences of separation on both spouses, and how the health effects of one spouse can affect the other. In complement, P-E exchange affords a practical framework for contextualizing the meaning and significance of couplehood within the LTC environment. The framework lends understanding to the interplay of A-B dynamics within the developmental outcomes of identity and autonomy and their role within spouses' shared sense of identity and how the socio-physical environment of LTC can challenge couples' abilities to preserve their relationship post-relocation. Moreover, providing a valuable tool to critically evaluate the socio-physical environment of LTC that impacts a couple's preservation of relationship when one spouse has dementia.

Used in complement to one another, the two theories provide a holistic and insightful approach to investigating spousal relationships in LTC. These unique perspectives will contribute to our understanding of the meaning and significance of couplehood, how the environment and culture of LTC influence marital relationships, and the strategies couples employ to maintain their relationship within the situation. These insights can be translated into government policy, used to develop supportive interventions, inform person-centred care practices, and re-design and structure LTC settings to support to unique needs of married couples.

Chapter 3.

Literature Review

Despite the recognized importance of the marital relationship in older adults' lives, a critical evaluation of the practice of separating dyads when one spouse has dementia in LTC settings in academic research has been widely overlooked. Consequently, this scoping review aims to present an overview of the current literature on the impact of separation on couples when one spouse has dementia and the challenges, they may face in maintaining their desired relationship. A scoping review is appropriate because it allows for the identification of key themes and knowledge gaps by providing a comprehensive overview of the relevant literature within an under-researched topic of study (Levac et al., 2010). To date, there has not been an extensive review completed to examine the impacts of the involuntary separation of married couples in LTC settings when one partner has dementia on relationship quality and couplehood, as well as how the socio-physical environment of LTC influences these couples' abilities to maintain their relationship.

This chapter will first describe a profile of older adults and their related risks and trajectories to a collective LTC relocation. The information offered in this profile was not identified in the examined articles and therefore is not part of the scoping review. However, it is included for context to illustrate married couples' various avenues to LTC settings. Next, the methodology used to conduct the review will be outlined. Finally, the findings of the review and the discovered four substantive themes and their central concepts will be summarized and examined. These four themes include: Physical Separation: Impacts on Relationship and Health/Well-being, The Significance and Meaning of Visiting, Social Environment, and Physical Environment.

According to the 2011 Census of Population and General Social Survey (GSS) of Canada, 56.4% of seniors aged 65 years and over lived as part of a couple (Statistics Canada, 2011). Furthermore, revealing that 49% of older couples are age-homogamous, with an average of three years between spouses (Statistics Canada, 2011). In consideration, research reveals that a couple's relocation to LTC settings can be in response to both collective and individual health needs. A study completed by Kemp

(2008), which examined 20 couple’s trajectories to LTC settings, described a couple’s health trajectory and risk for relocation as either synchronous or asynchronous (Kemp, 2008). Synchronous is described as “spouses experiencing health declines at relatively similar rates, while asynchronous, is referred to when relocation was motivated primarily for the needs of one spouse” (Kemp, 2008, p. 239). For many of the older couples in the study (many of whom had a spouse with dementia), it was further revealed that one spouse often assumed a caregiving role to the other before relocation (Kemp, 2008). Thus, indicating that although asynchronous couples may relocate for the sake of their spouse, the presence of caregiving responsibilities can increase collective risk (Kemp, 2008).

These findings align with Schulz and Sherwood (2008), who mention the influence of larger social determinates of health such as older couples’ socioeconomic status and shared health practices. The authors note that spousal caregivers with a lower socioeconomic status may experience greater difficulty in a caregiving role given economic circumstances (Schulz & Sherwood, 2008). Also, that the collective health declines experienced can result in the necessity for both spouses to relocate (Schulz & Sherwood, 2008). Prominent health transitions are in accordance with the studied risk factors for LTC admission, concerning one or both spouses while they reside independently at home (Kemp, 2008). Factors most frequently stated include age, mobility deficits, limited abilities to perform activities of daily living (ADL’s) (e.g., toileting, dressing, and personal hygiene) and instrumental activities of daily living (IADL’s) (e.g., house maintenance, cooking, and bill payments), hospitalization, and dementia (Andel et al., 2007; Bharucha et al., 2004; Koppitz et al., 2017).

The presence of dementia is often highlighted in research as a critical indicator for LTC relocation since symptoms significantly impact an individual's capabilities to function independently (ADL's) and consequently increase the occurrence of caregiver burden (Andel et al., 2007). According to the Canadian Institute for Health Information’s (CIHI) analysis “about one-third of seniors younger than 80 who’ve been diagnosed with dementia live in long-term care homes, [with] the proportion increase[ing] to 42% for those 80 and older” (Canadian Institute if Health Information (CIHI), 2018, para. 2). In addition, Friedman et al. (2005) found that chronic conditions such as responsive behaviours and incontinence were demonstrated as prominent predictors of individuals with dementia, as well as their caregiver's need for their partner's LTC relocation (Friedman et al., 2005).

Older spousal caregivers (aged 75 years and older), in particular, are noted in research to experience poorer physical and emotional health as a result of balancing caregiving with household demands (Andel et al., 2007; Wijngaart et al., 2008). This notion is emphasized by Monin et al. (2019) which found that older spousal caregivers, who often experience their own health declines, are challenged with the ability to care for their partners as well as themselves. These findings are aligned with Buhr et al. (2006), which highlighted that, together with their spouses progressing dementia, older spousal caregivers were more likely to indicate that their own declining health was the impetus for LTC.

Lastly, for both synchronous and asynchronous couples, it was found that hospitalization was an essential indicator of the risk of relocation. Hospitalization from an acute illness such as stroke(s) or a determinantal fall or series of falls, is linked to a quick/unexpected change in health status that can result in the unplanned necessity of LTC (Buhr et al., 2006; Koppitz et al., 2017). To illustrate, Koppitz et al. (2017), revealed that "for [older adults] over the age of 85 years, a hospital stay is perceived as a direct predictor of admission" (p. 517). Stating that, the physical and cognitive decline as a result of hospitalization can alter an individual's capability to function independently (Koppitz et al., 2017). In these situations, Kemp (2008) explains that the relocation process can become rushed and consequently more difficult to find accommodations for both spouses, and therefore couples relocate due to an LTC settings vacancy instead of preference. Further revealing that couples made the decision to relocate to an LTC setting (e.g., nursing homes or assisted living) with the hopes of remaining together (Kemp, 2008). This notion proved particularly relevant for asynchronous couples, suggesting that for the spouse who did not necessarily require the support of LTC, the decision to move involved “personal sacrifice” and the motivation to gain the necessary care for their spouse (Kemp, 2008, p. 241; Torgé, 2020).

3.1. Method

Two core research questions guided the scoping literature review: 1) How does the current practice of separating married couples between LTC settings (including AL and IL) when one spouse is living with dementia and resides in LTC impact the marital relationship and couples' abilities to sustain couplehood? and 2) How does the LTC socio-physical environment influence couples' opportunities to maintain their relationship? Noting the lack of empirical research on older couples who reside in LTC together, the search strategy involved broadening the scope to include publications that explore the experiences of visiting spouses and their abilities to maintain the quality of their relationship within LTC as well as grey literature to inform the core focus. This strategy follows the framework outlined by Arksey and O'Malley (2005) and the principles of Levac et al., (2010). The chosen methodology follows similar stages as other popular methodologies such as Joanna Briggs Institute (JBI) methodological guidelines or the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR), such as the identification of a research question, broad searches, refining of search criteria/inclusion criteria, and the charting and summarizing of findings. However, Arksey and O'Malley (2005), which was expanded by Levac et al. (2010), was chosen because it allows for the critical evaluation of results and consideration of findings in broader contexts, such as implications for future research, policy, and practise, which is not typically a component of other scoping review methodologies like JBI or PRISMA-ScR (Lockwood et al., 2019).

The review involved five stages: (1) identifying the research question, (2) identifying relevant studies, (3) study selection, (4) charting the data, and (5) collating, summarizing and reporting the results (Arksey & O'Malley, 2005; Levac et al., 2010). Using the two research questions mentioned above, relevant studies were identified by conducting broad searches using several databases, including Ageline, Simon Fraser University (SFU) Catalogue, PsychINFO, and Google Scholar. Search keywords were used in combination with one another. They included: "long-term care" or "nursing home" or "residential care" or "assisted living," "couplehood," marital relationship" or "marital quality," "dementia," "separation," "spousal caregiver(s)," "staff awareness," "care home design" or "physical environment," "health impact," and "family visits" (e.g., "long term care" + "martial relationships" + "dementia"). Inclusion criteria involved research published in English from 1994 to 2020 and includes any relevant empirical and original non-empirical research, thesis, reviews, and commentary articles deemed important and pertinent to the capstone topic and research questions. Additionally, the reference lists of relevant articles were also searched.

In the third stage of study selection, more rigorous inclusion and exclusion criteria were adopted. Inclusion criteria in this stage involved having literature that (a) focused on spousal relationships when one has dementia, (b) were situated in LTC settings (e.g., nursing homes, AL, and IL), and (c) aimed to understand the impacts of the LTC socio-physical environment on spousal relationships. Publications were excluded if they did not focus on spousal relationships when one has dementia, did not include a majority sample of participants that were spousal caregivers, and did not provide insight into LTC settings' impacts on couples' relationships. Such publications focused explicitly on the relocation process to LTC, spousal caregiver burden, end-of-life care for persons with dementia, and couples who remained living together in their own homes.

The reference management software, Mendeley version 1.19.4 was used to systematically sort for duplications, manage references, and organize the publications. The fourth stage involved charting the data. Following the search process, publications were chartered according to a "descriptive-analytical" method, which involved recording the publication's fundamental information (Arksey & O’Malley, 2005, p. 26). According to Arksey and O’Malley (2005), “charting describes a technique for synthesizing and interpreting qualitative data by sifting, charting and sorting material according to key issues and themes” (p. 27). Publications were charted within the following categories: "author(s), year of publication, and location," keywords, the focus of study, methodology, and key findings (Appendix A). (Arksey & O’Malley, 2005, p. 27). In the final stage of collating, summarizing, and reporting the results, two forms of analysis were completed. First, descriptive statistics were obtained from each study such as geographical distribution, research design and methodology. In doing so, enabling the identification of the central concepts (Arksey & O’Malley, 2005). Second, the literature was coded and organized thematically to determine key concepts (Arksey & O’Malley, 2005; Levac et al., 2010). The literature was then synthesized and used to shed light on how the LTC socio-physical environment's characteristics impact a couple's abilities to maintain their relationship post-relocation.

3.2. Findings

The database search generated 145 publications. A supplementary 22 were obtained from the reference lists of other publications and broader Google searches. A total of 30 publications were included in this review. Figure 1 presents a flow diagram of this reviews search strategy. As illustrated in this Figure, following the screening and eligibility assessment procedures, 38 full-text articles were reviewed. Eight articles were excluded based on the relevancy of the content to the topic at focus. For example, they were omitted because they did not focus on dementia or did not include a large enough sample of participants whose spouses had dementia, did not focus on LTC settings, focused solely on the transition to LTC settings, and did not provide insight into the marital relationship post-relocation. Moreover, three of the included publications were considered exceptions since they provide essential insight into the socio-physical environment of LTC settings that impacts couples.

Finally, a total of 30 articles were reviewed. Of these publications, the majority (n=27) used a qualitative design, two were literature reviews, and five fell into the category of grey literature. Most publications were authored in the United States (n=7), Canada (n=7), England (n=4), and Norway (n=4), Sweden (n=4), and Australia (n=4). Of the Canadian studies, only three took place in B.C. Only one publication, a discussion paper out of Australia, offered insight into the perspective of persons with dementia. Although two other publications (Torgé, 2020) and (Malone, 2016), included persons living with dementia in their samples, their studies did not emphasize their viewpoints. Just six publications had both spouses reside in LTC settings.

This review has a few limitations. First, utilizing a scoping review approach has some weaknesses since it provides a broad overview of the available body of literature on a specific topic (Pham et al., 2014; Sucharew & Macaluso, 2019). Thus, this methodology does not provide an opportunity for much in-depth critical appraisal of the reviewed studies. For instance, it does not enable a more nuanced critique of individual studies regarding their specific limitations, such as small sample sizes and related sampling or generalizability in terms of the population studied, location, and the study time frame. This poses a significant limitation as the lack of critical appraisal leaves it challenging to identify discrepancies in studies as well as an ability to translate results into recommendations and future research design strategies.

Furthermore, despite my best efforts to be as comprehensive as possible, it's likely that I have overlooked certain publications (e.g., “grey” literature) that could have offered useful information due to the explicit inclusion criteria. Moreover, the search did not include literature published in other languages. In addition, because of the specificity of the reviewed topic, broader generalizability and applications to other areas are limited. Additionally, several studies were completed by the same authors, which reduces the scope of studies reviewed, although this observation illustrates the paucity of research in this field. Lastly, although a formal assessment of disciplinary or other research biases is not required for a scoping review, it is important to acknowledge some potential issues. For example, my review involved a selection of articles that leaned towards a more psychosocial areas of focus.

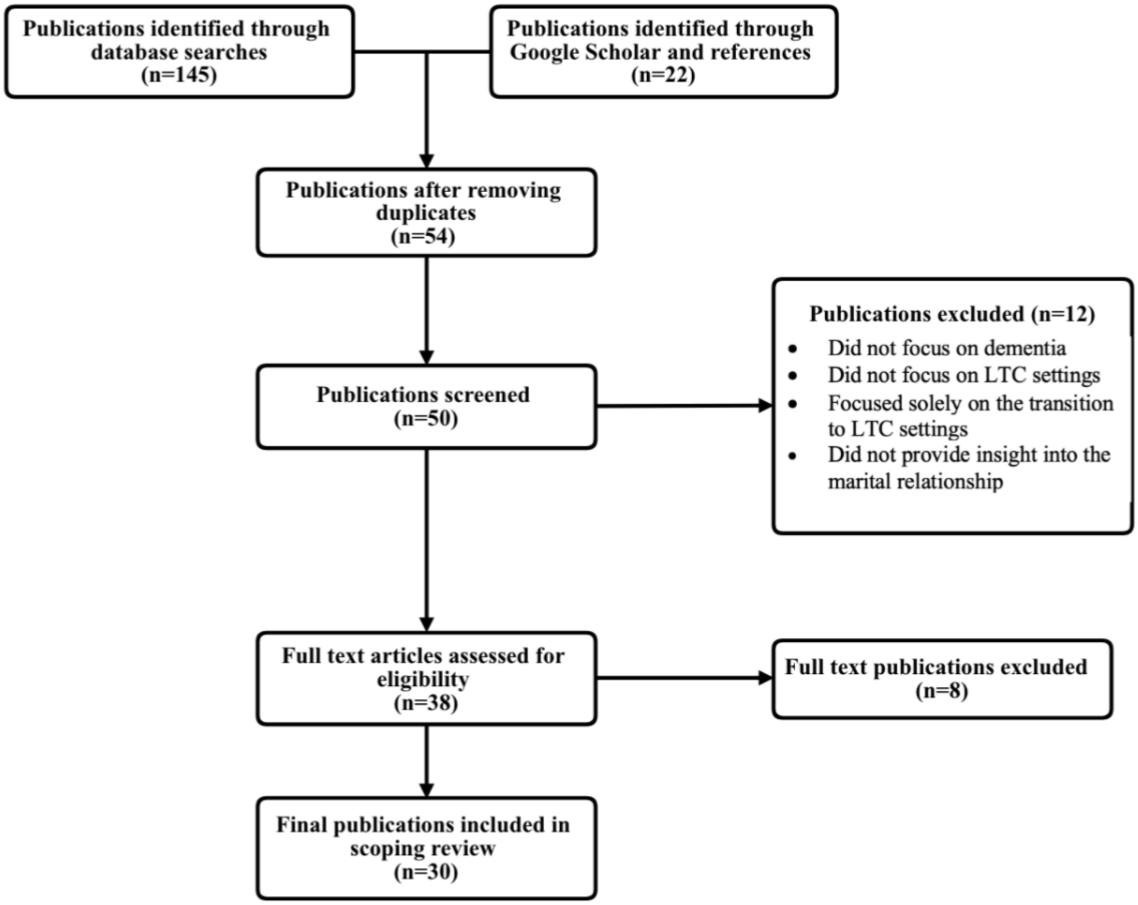


Figure 1. Flow diagram of scoping review process

Analysis of the publications identified several intersecting variables that can impact couple's sustainment of their desired relationship quality post relocation to LTC settings. The publications revealed an intrinsic grouping of topics in which four broad themes were developed: Impact of Physical Separation on Relationship and Well-being, Significance and Meaning of Visiting, Social Atmosphere and Relationships, and Physical Environment. It is significant to note that the progression of dementia is strongly entwined into the experiences of couples' marital relationships and engagement in LTC settings. The progression of dementia and subsequent symptom's, therefore, are interwoven throughout each theme. Several subtopics highlighted in the literature overlap and can be discussed within multiple themes. Therefore, a decision was made to discuss these subtopics within the most closely aligned general theme. Table 1. illustrates the discovered themes and related subthemes.

Table 1. Summary of themes and related subthemes

Theme	**Description**	**Subthemes**
Impact of Physical Separation on Relationship and Well-Being	The varied emotional sensations associated with couples' physical separation and losing couplehood are depicted.	• Compounding losses and Grief • Struggling with Guilt/relief • Perspectives of Persons Living with Dementia
Significance and Meaning of Visiting	Routinely visiting was determined to combat loneliness and loss of couplehood. Visiting was also a means to stay involved in care and to continue their relationship.	• To uphold marital vows and preserve their relationship • Arranging visits to enable meaningful exchanges and ease goodbyes • To monitor care quality and advocate
Social Atmosphere and Relationships	Describes the social environment of LTC settings and couples' social relationships and their impact on couples' abilities to maintain their desired relationship quality.	• Relationship with care staff • Couples' social relationships • Infidelity • Sexual orientation
Physical Environment	Illustrates how the design and structure of LTC settings influence visiting spouses' abilities to engage with their partner.	• Private bedrooms • Privacy • Public Spaces

3.3. Summary of Themes and Central Concepts

The four presented themes and their related subthemes provide insight into the unique experiences and circumstances that impact the sustainment of spousal relationships in LTC settings. The order in which the themes are presented is intended to mirror a natural progression of events and experiences related to adjusting to physical separation from one's spouse, having one's spouse transition to LTC, and how spousal caregivers maintain elements of their relationship within the LTC environment. Notably, the progression of dementia is indicated in each theme as a principal feature affecting a couple's relationship, sense of couplehood, and their engagement/experiences in LTC settings. Equally, the themes and their related subthemes showcase and warrant that couples' needs and experiences should not be viewed as interchangeable, as individuals may have varied needs regarding their participation in their spouses' care and definitions of relationship quality.

The order is as follows: Impact of Physical Separation on Relationship and Well-being, Significance and Meaning of Visiting, Social Atmosphere and Relationships, and Physical Environment. As demonstrated, the emotional impacts on relationships and health/well-being resulting from physical separation will be discussed first. Second, spousal caregivers' efforts to mitigate these losses and preserve their relationship through visitation will be revealed. Finally, the last two themes touch on LTC settings' social and physical environment in which spousal caregivers must face and adapt to new relationships, such as care staff and environmental barriers such as searching for privacy.

3.4. Impact of Physical Separation on Relationship and Well-Being

This theme illustrates the dynamic emotional experiences related to couples' physical separation and losing couplehood. The permanence of physical separation from one's spouse as a result of LTC relocation was demonstrated in the literature to be a complex and overwhelming emotional experience (e.g., Førsund et al., 2015; Hemingway et al., 2016; Hunt, 2015; Mullin et al., 2011; Glasier & Arbeau 2019). The emotional impacts of separation on relationship and health/well-being were touched upon in nearly every publication of this review (n=25). It is important to note that the emotions discussed are strongly interwoven and can be felt simultaneously. In particular, the separation generated an initial process of grieving over the compounding losses of their involuntary separation, their relationship identity, and their spouses' progressive deterioration of cognitive abilities (Førsund et al., 2015; Hemingway et al., 2016; Miskovski, 2017). The following sections will describe two concepts that capture the emotional complexities connected with couple's physical separation: Compounded Losses and Grief and Struggling with Grief and Guilt/Relief. Additionally, this section will highlight the one article that presents the perspectives of persons with dementia.

***Compounding Losses and Grief*.** For spouses of persons with dementia, "the relocation of a partner indicates not only a physical separation, [but] must be considered an experiential separation from a relationship filled with memories of a life course with their partners" (Førsund & Ytrehus, 2018, p. 860). Their partner's absence in daily routines was shown to create the overwhelming feeling of suddenly 'being alone' (Førsund et al., 2015; Hemingway et al., 2016; Hennings & Froggatt, 2019; Mullin et al., 2011). Førsund, Skovdahl, Kiik, & Ytrehus's (2015) study, which explored spouses' experiences of losing couplehood with their partner living in LTC, characterized this concept as the "loss of a shared everyday life" (p. 125). In the article, one participant expressed these feelings *"as a sense of emptiness: an empty chair, empty bed, explaining how he experienced the absence of his wife as a physical non-presence"* (Førsund et al., 2015, p. 125). Hunt's (2015) study explored the emotional consequences of placing a spouse into LTC and emphasized the powerful feelings of loss accompanied by the physical separation from one's spouse. The author explains that for spousal caregivers, their partners' transition to LTC means a complete adjustment to their "whole way of life" (Hunt, 2015, p. 50). Spousal caregivers expressed a loss of companionship, communication, and affection in their daily life with sentiments such as 'eating alone' or 'sleeping alone' (Hunt, 2015). Equally, the literature emphasized that spousal caregivers experience a loss of identity within the multiple losses and changes (e.g., Glasier & Arbeau 2019; Hunt, 2015; Miskovski, 2017; Hemingway et al., 2016; Tilse, 1994). For example, Hennings and Froggatt (2019) found that spousal caregivers felt unmarried or widowed and mourned the loss of their spouse and their relationship, and in turn, their identity as being a married person.

The progression of dementia was consistently revealed to be intensely interconnected with the feelings of loss and loneliness (e.g., Høgsnes et al., 2013; Hunt, 2015; Gladstone 1995a, 1995b; Mullin et al., 2013; Sandberg et al., 2001). In particular, the symptom of dementia that results in loss of speech was highlighted as challenging to the preservation of their relationship since it "interfered with the spouses' ability to be connected to their partner and hindered them from participating in their partner's everyday life" (Førsund et al., 2015, p. 125). Furthermore, spousal caregivers live through their partners' continuous decline in abilities to remember the couples shared experiences, including family members (e.g., children and grandchildren), significant life events, and objects/places of meaning (Førsund, 2017; Hennings et al., 2013; Mullin et al., 2013); as Førsund et al., (2015) state, "they [are] alone with memories from a lifetime together" (p.16). This notion aligns with the Alzheimer's Australia NSW (2017) discussion paper that examined the relationship changes between persons with dementia and their family caregiver (a majority of whom were spouses), which notes that communication lies at the heart of the relationship and emotional intimacy between spouses. Therefore, losing the aspect of sharing daily experiences, discussing topics of interest and/or importance, or even banter changes the nature of their relationship (Miskovski, 2017). The loss of physical intimacy was also shared to be an impactful feature contributing to spousal caregivers feelings of loss and loneliness (Malone, 2016; Miskovski, 2017). Consequently, articles highlighted that due to their partners progression of dementia spousal caregivers may feel lonely within the spousal relationship even prior to relocation, however, that living separately may exaggerate the emotional distance of their present relationship which can increase experiences of depression (Førsund, 2017; Hennings et al., 2013; Høgsnes et al., 2013; Hunt, 2015; Miskovski, 2017; Mullin et al., 2011).

In addition, to feeling disconnected from their spouse, the transition to LTC and their 'involuntary separation was determined in the literature to spark experiences of grief and mourning over the loss of relationship with their spouse (e.g., Hunt, 2015; Høgsnes et al., 2013; Førsund et al., 2015; Førsund, 2017; Miller, 2016; Watterson, 2017; Glasier, 2016, Glasier & Arbeau, 2019). Understanding the personality changes that occur as the disease progresses, spousal caregivers were described in the literature to experience the concepts of anticipatory grief, the anticipation of loss, and ambiguous loss, in which individuals grieve the loss of their loved one's lack of cognitive presence, while they are still alive (Førsund et al., 2016; Førsund, 2017; Førsund et al., 2015; Glasier, 2016; Glasier & Arbeau, 2019; Hemingway et al., 2016; Høgsnes et al., 2013; Miskovski, 2017). The concepts of anticipatory grief and ambiguous loss was noted as a principal feature of the experience of dementia within the marital relationship (Hennings et al., 2013; Mullin et al., 2011). To illustrate, in Hennings et al.'s. (2013) study participants' feelings of grief were explained as interminable, which cannot be interrupted without the finality of their partners' death. Similarly, caregiving spouses within Høgsnes et al., (2014) study expressed their on-going need to cope with the loss of "the person they married, who no longer existed, although their physical appearance was the same" (p. 156). In consideration, anticipatory grief was reported to be an apparent aspect throughout their partners' progression of dementia and intensified through LTC placement, while ambiguous loss was demonstrated as more of an ongoing emotionally intense experience contributing to the loss of couplehood (Førsund et al., 2016; Førsund, 2017; Førsund et al., 2015; Høgsnes et al., 2013; Miskovski, 2017). Furthermore, it was revealed that spousal caregivers mourned the loss of a future with their spouse (Førsund et al., 2015; Førsund, 2017; Hemmingway et al., 2016; Tilse, 1994,1998; Mullin, 2011). Their partners progressing dementia compounded with their 'involuntary separation' from their partner provoked the realization that plans, and new experiences together will no longer happen (Førsund et al., 2015; Førsund, 2017; Hemmingway et al., 2016; Tilse, 1994, 1998). Similarly, Mullin et al. (2011) identified spousal caregivers' anxieties towards the future of their partners' deteriorating health status and their own health status in terms of continuing caring/advocating for their partner.

Lastly, in close connection with grief, many spousal caregivers revealed having symptoms of depression (Braithwaite, 2002; Førsund, 2017; Glasier, 2016; Glasier & Arbeau, 2019; Hunt, 2015). As Hunt (2015) explains, for caregiving spouses, "most of their married life revolved around his or her spouse, and during the later years, their meaning and purpose may have centred in caring for their spouse" (p.50). Therefore, there is a dramatic change in lifestyle when their spouse transitions to LTC (Hunt, 2015). In connection, Gladstone (1995a) expressed that spousal caregivers can experience a loss of purpose after their partner's relocation. The author stated that spousal caregivers could experience depression over losing their daily routines and responsibilities that often revolved around providing their partner care (Gladstone, 1995a). Consequently, it was revealed that spousal caregivers in turn can experience stress and anxiety around their partners well-being and the quality of care provided in their absence (Hunt, 2015).

Struggling with Grief and Guilt/Relief. Fourteen articles revealed conflicting emotions between spousal caregivers' grief and the guilt/relief they may feel after relocating their partner to LTC (Høgsnes et al., 2013; Braithwaite, 2002; Førsund et al., 2015; Førsund et al., 2016; Førsund, 2017; Hennings et al., 2013; Sandberg et al., 2001; Hunt, 2015). Spousal caregivers' decisions to place their partner in care were often met in the literature with emotions of guilt and a failure to uphold marital vows/obligations (Førsund et al., 2016; Førsund, 2017; Førsund et al., 2015; Glasier & Arbeau, 2019; Hennings & Froggatt, 2019; Høgsnes et al., 2013; Hunt, 2015; Tilse, 1994). As Høgsnes et al. (2013) explains, since the “decision about relocation could not be a joint decision between the spouse and the person with dementia,” spousal caregivers feel guilty as they feel they have deceived their spouse (p. 156). Similarly, Miller (2016) illustrates that although spousal caregivers feel a sense of relief with caregiving duties mitigated and recognize that their partner is getting the appropriate care, this is a mixed emotion as there are conflicting feelings of guilt of essentially abandoning their partner. On the other hand, spousal caregivers in the literature expressed a sense of freedom and relief as many elements of caregiver burden are alleviated after placement (Høgsnes et al., 2013; Miller, 2016; Miskovski, 2017; Watterson, 2017). This notion aligns with Gladstone’s (1995a) study in which one or both spouses relocated to LTC, which revealed that the separation of spouses to reside in different rooms/sections when one has dementia is based on the belief that it will provide respite for the caregiving spouse.

Yet, some spousal caregivers in studies expressed feelings of frustration and resentment towards their partners (Glasier & Arbeau, 2019; Miskovski, 2017; Watterson, 2017). In following couplehood typology Kaplan's (2001), those with the lowest form of couplehood, “Unmarried marrieds”, characterized their relationship and marriage as being over, and are grieving or have completed grieving the loss of their spouse, expressed resentment and towards their spouse as a means of coping with these losses. For example, it was found that feelings of anger and resentment were "directed at the institutionalized spouse for not taking better care of him or herself and 'ending up in a nursing home'" (Kaplan, 2001, p. 95). These emotions, along with recognizing that their partner is getting the necessary care in a supportive environment, were viewed to reduce the feelings of guilt surrounding LTC placement (Kaplan, 2001; Miller, 2016; Torgé, 2020; Watterson, 2017).

Perspectives of Persons with Dementia. Remarkably, only one publication offered some insight into the perspectives of persons with dementia. The Alzheimer's Australia NSW (2017) discussion paper explored the relationships of family careers (the majority of whom were spousal caregivers) and the voices and experiences of persons with dementia. Most notable was the feeling of loss of identity (Miskovski, 2017). People with dementia expressed a loss of independence due to changes in their spousal relationship dynamic, compounded with the multiple personal losses that occur with progressing dementia (e.g., loss of driver's license) (Miskovski, 2017). For example, it was expressed that like spousal caregivers the change in role to being cared for was a significant shifting point in their sense of identity and their relationship with their spouse (Miskovski, 2017). Persons with dementia described feelings of guilt towards the 'burden' they are inflicting on their spouse and symptoms of depression in response to their diagnosis and progressive memory loss, and loss of their previous life and independence (Miskovski, 2017). For example, a woman with dementia explained:

> *The relationship [with my husband] has changed. I am more enclosed in myself. I don't feel I want to speak about things. I have hated losing my independence and having to rely on someone. I don't feel as attracted to him. I feel guilty that I'm changed. I am more changeable in my emotions. It is hard for him. I feel he speaks down to me* (p. 6).

3.5. Significance and Meaning of Visiting

To combat feelings of loneliness and loss of couplehood, the majority of articles (n=24) revealed that caregiving spouses would routinely visit their partner. Visiting was demonstrated to help spouses deflect their feelings of loneliness, served as a means of maintaining involvement in care, and “provided opportunities to express continuing attachment and obligation” (Tilse, 1994, p. 172). The research illustrated three categories of how spouses used visiting to sustain their relationship and adapt to the changes brought on by their partner's dementia advancement: 'to uphold marital vows and preserve their relationship,' (n=11) 'arranging visits to enable meaningful exchanges and ease goodbyes,' (n=10) and 'to monitor care quality and advocate' (n=12).

To uphold marital vows and preserve their relationship. Visiting regularly "seemed to lessen [spouses] longing for their partner [and] sustained their sense of still playing significant roles in their partners' lives" (Førsund et al., 2016, p. 3015). Tilse's (1997) study, which explored the intent and meaning behind visiting a spouse in LTC, found that visiting provided the ability to continue aspects of a couples' daily life and sustain an emotional connection. To illustrate, visiting was demonstrated to enable opportunities for intimate moments, reminisce, and participate in activities together, ultimately helping to cope with the feelings of loneliness associated with being separated (Tilse, 1997). In a similar vein, Førsund et al. (2016) discovered that visiting served a pivotal role in their ability to continue their relationship quality through their separation and the progression of their partner's dementia. The authors also stated that visiting provided spouses with the ability to recreate their shared routines and participate in activities together (e.g., "such as looking at photographs, reading family histories, playing cards, relaxing, drinking coffee together, reading the paper and making small talk"), enabling the much-needed sustainment of sense of companionship (p. 3019). Furthermore, Hunt (2015), found that couples who were able to remain sharing meals together had lower rates of weight loss/malnutrition as well as decreased symptoms of depression. Likewise, the ability to participate in activities together supported the couple's sense of couplehood, as the activities promoted the sharing of new experiences and continued conversation (Hunt, 2015). Irrespective of couples' expression of togetherness during visits, the progression of dementia was iterated in the literature to impact their expressions of couplehood, often demonstrated through physical embraces (e.g., holding hands or stroking their partner's hair), especially when verbal communication became challenging and their partner's lucidity fluctuated (Førsund et al., 2016; Hunt, 2015).

Marital vows to stand by their partner 'in sickness and in health, till death do us part' were discussed in the literature (n=10) and were shown to play a key role in couples' perceptions of the importance of their relationship and their desire to continue being involved in their partners care (Førsund et al., 2016; Glasier & Arbeau, 2019; Hemingway et al., 2016). The notion to fulfill their marital promises is reflected in Hunt's work (2015), who discovered that marital vows were taken in verbatim for some caregiving spouses, promoting a sense of duty to be present for their partner and ensure that they had quality care and had a quality of life within the home. For example, one participant in Hunt's (2015) study stated, *"It is my duty for better or for worse. This is for the better for her, and I have to put up with the worse"* (p.117). This notion was reiterated in Hemingway et al.'s (2016) study, which focused on gaining a deeper understanding of the experiences of spouses of persons with dementia who reside in LTC, which described marital vows as a central motivator for spouses to continue playing a role in their spouses care post-relocation.

Similarly, in following Kaplan's (2001) couplehood typology, Braithwaite (2002) found that for spouses who viewed their marital vows in verbatim, their perception of their spouse and the marital relationship did not change despite their partner's dementia progression exhibited a high sense couplehood. Having a high sense of couplehood in the study meant that spouses "did not differentiate between the marital past and present in their assessment of feeling married" and were more likely to "refer to themselves as part of a couple, using "We," rather than "I." (Braithwaite, 2002, p. 174). For these spouses, visiting represented a continuation of their relationship, often talking about their marriage in the present tense even though their relationship's circumstances have changed (Braithwaite, 2002). This notion of unconditional love and devotion was mentioned in a number of articles which found that despite their partners progressing dementia and being physically separated, that many spousal caregivers’ strong commitments and love for their spouse did not change (e.g., Tilse, 1994; Watterson, 2017; Miskovski, 2017; Førsund, 2017; Mullin et al., 2011). In light of the significance of their marital relationship in their lives, physical separation resulting from relocation felt akin to divorce and "emphasized the separateness of their lives" (Tilse 1997, p. 202, Hemingway et al., 2016; Hunt, 2015). This finding relates to Glasier and Arbeau's (2019) study, which examined caregiving spouses' experiences of being involuntarily separated from their partner due to their partner's relocation to LTC settings. The study revealed that "to some, the separation felt like an "invalidation" of their wedding vows, and abandonment at the time when their spouses needed them the most" (Glasier & Arbeau, 2019, p. 467).

In contrast, Watterson (2017) noted that some spouses believed that their vows held them back from their abilities to move forward. Further revealing that individuals' perceptions of marriage and marital commitments were not only "influenced by their own experiences of marriage but also from the expectations of other people" (Watterson, 2017, p. 21). To illustrate, participants expressed that they felt judgment from their friends and family and care home staff about their role as a spouse to a person with dementia (Watterson, 2017). These judgments were said to fuel caregiving spouses' guilt about their contributions to their partner's care and the amount of time spent with them (Watterson, 2017). Consequently, reinforcing feelings of marital obligations to their spouse (Watterson, 2017). The notion of obligation to care for one's spouse was further iterated in Førsund et al.'s. (2016) article where one participant was legally divorced from her partner, however, continued to care for her ex-husband as a result of her feelings of obligation, however, still felt a sense of value in maintaining their relationship. However, most publications illustrated that, spouses felt an on-going love and devotion to their partner, although the nature of their relationship had changed (e.g., Kaplan, 2001; Watterson, 2017; Braithwaite, 2002; Hemingway et al., 2016; Hunt, 2015; Førsund et al., 2015; Førsund et al., 2016; Førsund, 2017).

Notably, Glasier & Arbeau’s (2019) study highlighted the critical barrier of facility location and access in spousal caregivers’ abilities to visit their partner. The authors found that concerning spousal caregivers’ difficulties in adjusting to the separation (e.g., loneliness and anxieties over the quality of care given to their partner), these feelings are intensified when there are considerable barriers in their abilities to visit their partners (Glasier & Arbeau, 2019). Having their partner reside in a geographically far facility from their homes provided obvious difficulties in gaining frequent transportation (Glasier & Arbeau, 2019). Participants in their study mentioned the financial challenges in gaining transportation (e.g., paying for taxi services), challenges resulting from bad weather, and their feelings of burdening others when asking for transportation (Glasier & Arbeau, 2019). Furthermore, their ability to move closer or live in the same LTC setting complex as their partner was also mentioned to be difficult due to the financial costs (Glasier & Arbeau, 2019).The study found these challenges to increase spousal caregivers’ feelings of loneliness and depression (Glasier & Arbeau, 2019).

Arranging visits to enable meaningful exchanges and ease goodbyes. In addition to visiting to preserve their relationship, it was evident in three articles that as their spouse's dementia progressed, it became necessary to schedule visits around activities of importance for their partners and times in which they may be more lucid (Førsund et al., 2016; Glasier & Arbeau, 2019; Miller, 2016). Scheduling visiting, therefore, provided spouses with the best opportunities to have meaningful interactions. Førsund et al.'s. (2016) study, which focused on the relationship of spouses of persons with dementia when their partner resides at LTC, found that the fluctuations of their partners' capacities throughout the day made it challenging to engage in conversations.

Spouses, therefore, took note of the times of the day their spouse may be more "awake and capable of interacting" and scheduled visits with them accordingly (Førsund et al., 2016, p. 3019). For example, one participated stated, *"I have to be there in the morning. Because he is very tired in the afternoon and then he gets so angry. I found out it is better when I visit in the morning."* (Førsund et al., 2016, p. 3019).

Similarly, Glasier and Arbeau's (2019) study, which examined the experience of older couples involuntarily separated due to one spouse's relocation to LTC, found that many spouses viewed visiting "as one of the most important things they can do to show their support" (p. 466). The establishment of visitation patterns was discovered to be a key method to participate in their spouse's life in a meaningful way throughout their partners' dementia progression (Glasier & Arbeau, 2019). By way of an example, a participant within the study who resided in the same multilevel care complex as her husband "established a pattern of regularly visiting at mealtimes to help... with his meals" (Glasier & Arbeau, 2019, p. 470). By doing so, she was able to continue her involvement in her husband's care and felt content in her abilities to *"positively influence her husband's well-being"* (Glasier & Arbeau, 2019, p. 470). Scheduling visits was also highlighted in Miller's (2016) study, which found that many caregiving spouses aimed to arrange visits with their partner during activities deemed necessary to their partners (e.g., fitness, religious services etc.) and mealtimes. Similar to Glasier's (2019) study, Miller found that for spouses of persons with advancing dementia, routinely assisting with feeding and hygiene was demonstrated to act as a meaningful way to engage with their spouse and stay present in their life.

In addition, scheduling visits around their partners' routines also served as a method to ensure goodbyes were done in a manner that avoided upsetting their partners. It was discovered that many spouses utilized mealtimes or scheduled activities "to leave their partners at the moment when new events were initiated and the personnel in the units could divert their partners' attention" (Førsund et al., 2016, p. 3019). As one participant stated in Førsund et al.’s (2016) research:

> *It is difficult every time. Therefore, I have to monitor and wait for mealtime. Then I have to persuade her to sit down at the table, before the personnel take over; they help her with dinner. Yes, when she sits down and starts to think about the food, then I can sneak out.* (p. 3019)

Saying goodbye was expressed as particularly difficult and an emotional experience in eight publications. One participant in Glasier’s (2016) study was revealed to have developed hand signals with care staff to distract his wife in order for him to leave without saying goodbye. In connection, Førsund et al., (2016) expressed that being able to leave their partner without their objection “increased their feelings of continuing their relationships because they could leave without the strong feeling of letting their partner down” (Førsund et al., 2016, p. 3019). These notions were further iterated in Hemingway et al.’s (2016) article as well as Gladstone’s (1995a), which revealed that leaving took an emotional toll on caregiving spouses, with spouses often feelings “quite upset” after visits, further decreasing the frequency of their visits in order to protect themselves from burnout and maintain their abilities to continue having a meaningful relationship.

To monitor care quality and advocate. Twelve publications revealed that as the ability to connect with their partner became increasingly challenging, some spousal caregivers utilized their visits as opportunities to check on the care their partners were receiving and advocate for changes (e.g., Tilse, 1994; Hemingway et al., 2016; Mullin et al., 2011; Sandberg et al., 2001; Glasier, 2016; Miller, 2019). Hemingway et al. (2016) found that with physical caregiving duties mitigated by LTC staff, spousal caregivers felt that their main role was to advocate for their partner. Braithwaite (2002) described the emotional and moral turmoil spouses face during the transition from their partner's primary caregiver to simply a 'visiting spouse.' The authors revealed that although the transition represented an added loss, many felt conflicted with their understanding of the benefits of LTC, such as their partner receiving their needed care, with their perceptions of adequacy in care (Braithwaite, 2002).

The need to take action and advocate for their concerns was determined in the literature to be a vital form of how spouses of persons with dementia show their ongoing support and devotion (Glasier, 2016; Glasier & Arbeau, 2019; Hemingway et al., 2016; Miller, 2016; Mullin et al., 2011; Sandberg et al., 2001). For example, in Hemingway et al. (2016) study, advocacy was described as a dynamic part of the spousal caregiver's role. Participants in this study "viewed their involvement as a way to ensure their spouse received the best care possible. Specifically, they strove to anticipate their spouses' needs and communicate these to staff" (Hemingway et al., 2016). Similarly, Tilse (1994) revealed that the purpose of monitoring the quality of their partner's care was to ensure that elements of their partner's identity were upheld. The role of advocacy was further expressed in the literature to take on a significant portion of spouses visiting time. Mullin et al. (2011) which characterized spouses using their visiting time to 'monitor' their partners care as 'visiting as surveillance', which refers to spouses' feelings of responsibility to utilize their visits to check if their partners needs were being met and their overall well-being. As one participant expressed, *"... I want to be here (in the nursing home) to convince myself that erm (.) she's (.) everything's OK"* (Mullin et al., 2011, p. 184). This finding aligns with Hennings et al., (2013), which found that spousal caregivers often visited to calm their anxieties about the care their spouse is being given. In connection, Sandberg et al. (2001) deemed this phenomenon as 'keeping an eye.' Spouses in this study were often concerned with the level of personalization of care, expressing that care staff view their spouse as another patient and thus care would rarely be given with the same sort of enthusiasm as it would if given by their spouse (Sandberg et al., 2001). Moreover, revealing that when spouses viewed care as inadequate, their visitations were more frequent, and their observation levels deemed more vigilant (Sandberg et al., 2001).

Common concerns about inadequate care included hygiene (e.g., teeth not being brushed on a regular basis), addressing incontinence needs, aid with feeding or food being served cold, and "a lack of staff and consistent staff (due to high turnover and sickness rates), a lack of stimulation for residents" (Mullin et al., 2011, p. 184; Sandberg et al., 2001). These findings are consistent with Miller's (2019) study in which spouses felt the need to strongly advocate for their partner's care needs and the need to evoke changes in the ways care is delivered. In this study, spouses expressed confusion and frustration at care staff when they would carry out care tasks themselves when they thought it was the responsibility of the care home staff (Miller, 2019). Similarly, Glasier et al.'s (2019) study examined the experience of involuntary separation of spouses when one partner has dementia and relocates to LTC. The authors found that spouses lack confidence in the quality of care being provided "weighed heavily on them…many report[ing] having trouble sleeping, especially on days when they were unable to spend much time with their spouse" (Glasier & Arbeau, 2019, p. 470).

Ultimately, taking action in response to their concerns, often resulted in minor changes that nevertheless instilled peace of mind as well as served as a way to remain involved in their partners lives post relocation (Glasier et al., 2019). Lastly, Braithwaite

(2002) as well as Mullin et al., (2011) further noted the concept of continued caregiving and described the impacts of 'care-focused visits' on the marital relationship. They emphasized that spouses' frustrations with care staff can take away from meaningful time and connection with their spouse, in turn, negatively affecting the quality of their relationship (Braithwaite, 2002; Mullin et al., 2011).

3.6. Social Atmosphere and Relationships

This theme describes the social environment of LTC settings and couples’ social relationships. The social culture of LTC settings was discussed (n=23) publications to play an influential role in the sustainment of couples' desired relationship quality post-relocation. Two core relationships were emphasized to influence the social atmosphere of LTC settings and couple abilities to maintain their desired relationship quality: spousal caregivers’ relationship with care staff (n=16) and couples’ social relationships with other residents (n=7). Additionally, this theme also incorporates the circumstances of infidelity (n=2) and sexual orientation (n=1).

Relationship with Care Staff. Care staff were mentioned in 16 publications as a key influence of LTC homes overall social atmosphere and a principal determinate in couples’ abilities to maintain their sense of couplehood (e.g., Hennings et al., 2019; Sandberg et al., 2001; Hemingway et al., 2016; Mullin et al., 2011; Tilse 1994, 1997,1998; Braithwaite, 2002; Førsund et al., 2015; Førsund et al., 2016; Førsund & Ytrehus, 2018; Torgé, 2018, 2020). How care staff perceive and support the role of spousal relationships in LTC settings was revealed to lie at the heart of relationships between staff and spousal caregivers (Braithwaite, 2002). To illustrate, although many spouses spoke positively about care home staff, acknowledging that they were grateful for the care their partner was receiving (e.g., Braithwaite, 2002; Hennings & Foggatt, 2019), their desire to continue caregiving and advocate for the quality of their partner's care was demonstrated to create challenging relationships with care staff (Sandberg et al., 2001; Torgé, 2020).

To illustrate, Sandberg et al. (2001) study explored the lived experiences of spouses of persons with dementia who placed their partner in LTC, discovered that compounded with the complex emotions connected with relocation (e.g., guilt vs. relief), spousal caregivers are suddenly "mov[ed] from a position where they had been the main provider of care to where they [feel] like an outsider" (p. 408). It was further found that all spousal caregivers in their study wanted to maintain a form of involvement in their partner's care post-relocation (Sandberg et al., 2001). However, spousal participation in care was often seldomly supported by care staff, often resulting in clashes between spousal caregivers aiming to "preserve the individuality" of their partner and care staff restricted by the systematic barriers that define their role and responsibilities (Sandberg et al., 2001, p. 409; Tilse, 1998).

Against the background of spouses intently visiting to monitor care, Hemingway et al. (2016) revealed that care staff viewed spousal caregivers' concerns as excessive or unreasonable, with spouses "complaining about 'lost items and things' such as misplaced laundry or other personal items [as well as] having expectations about their spouse's appearance that facility staff were unaware of" (Hemingway et al., 2016, p. 881). Granted, spousal caregivers considered the difference in care priorities between themselves and staff as a conflict source (Hemingway et al., 2016, p. 881). Comparatively, Mullin et al., (2011) revealed that spouses' visiting as surveillance' practices such as making sure their partners are getting sufficient nourishment and maintaining overall welfare (e.g., toileting/proper measures to deal with incontinence, hygiene, suitable stimulation, and upholding quality of life) was viewed by staff as an obtrusion to their work and routines (Mullin et al., 2011). In fact, all the studies that mention spouse and care staff relationships described how spouses' interventions' in care creates tensions, making it difficult to form a constructive relationship and consequently resulted in having staff resent spouses visiting (Braithwaite, 2002; Hemingway et al., 2016; Mullin et al., 2011; Sandberg et al., 2001).

Sandberg et al. (2001), also highlighted the matter of care staff approachability and the need for caregiving spouses to be the first to initiate a relationship. The authors discovered that "it was obvious to carers that staff were key figures [and] highly influential in determining the overall quality of life for their partner…therefore, engaged in a number of tactics to try and 'keep things sweet' between themselves and the staff" (Sandberg et al., 2001, p. 412). Meaning, spousal caregivers needed to feel out their relationship with care staff and test how care staff respond to comments regarding care (Sandberg et al., 2001). These initial interactions were often found to determine future exchanges (Sandberg et al., 2001). To demonstrate, the staff gave the impression to relatives that concerns, and feedback would be supported and encouraged; however, when concerns were raised, spouses were met with misanthropic responses, with following exchanges feeling cold (Sandberg et al., 2001). However, Førsund (2017) claims that, over time, if spouses regularly visit, they are more likely to develop a positive relationship with staff, even so, emphasizing that it is often still a slow process.

Tensions between care staff and spousal caregivers were caused by conflicting knowledge of an educated understanding of the disease progression and spousal caregivers' understanding of their partner as a person (Sandberg et al., 2001). Care staff's knowledge of the behavioural changes that follow perhaps desensitizes them to the loss of the person that their relatives are experiencing (Sandberg et al., 2001). For example, Hemingway et al. (2016) described spouses' confusion and skepticism concerning the medications and dosage being given to their partner, explaining that "some spouses expressed lack of trust in medications or doctor's prescriptions and felt that the progression of the disease was at times accelerated, rather than helped, by medication" (p. 883). The apparent conflicting knowledge of care staff and spouses' created disagreeing ideas about care priorities and the understanding of a persons with dementia needs (Braithwaite, 2002; Hemingway et al., 2016; Hennings & Froggatt, 2019). Specifically, spousal caregivers' inherent knowledge of their partners' personality, preferences, and daily routines lead to the interpretation of behavioural changes to "not be attributed to [the] disease by rather to [their partners] personality and the particularities of [their] likes and dislikes" (Hemingway et al., 2016, p. 883). Nevertheless, the publications acknowledged spousal caregivers' feelings of respect, empathy, and gratitude towards care staff (e.g., Glasier 2016; Watterson, 2017; Mullin et al., 2011; Miller, 2016). To illustrate, spousal caregivers in Førsund and Ytrehus's (2018) study mainly identified care staff as kind and compassionate, making gestures such as offering coffee to make spousal caregivers feel comfortable while visiting.

In general it was expressed that care staff often do not understand the integral role spouses have on their partners' lives, and thus, many spouses feel the need to defend the spousal role (Braithwaite, 2002; Tilse, 1994). Likewise, the lack of recognition left spouses feeling unacknowledged and unsupported in the navigation of their partner's cognitive decline and the emotional losses connected (Braithwaite, 2002; Hemingway et al., 2016; Hennings & Froggatt, 2019). Additionally, the care staff's lack of inclusion of spouses in recreational activities and meals further enhances the emotional separation they feel from their spouses (Braithwaite, 2002; Hemingway et al., 2016). Therefore, it was revealed that care staff are central in aiding spouses understanding of the behavioural and cognitive changes of their partners progressing dementia and their transition from being the primary caregiver (Braithwaite, 2002). "However, many staff members do not have sufficient time, training, or motivation to be able to manage these interactions successfully" (Braithwaite, 2002, p. 163).

By contrast, Torgé (2018, 2020) studies which explored the perspectives of spousal carers who were permitted to live in LTC with their spouse due to Sweden's "cohabitation guarantee" legislation, present an intriguing perspective on the structure of care for married residents and care staff and spousal caregivers of cooperation. The studies revealed that many spousal carers expressed conflicting feelings regarding their role in LTC, indicating that even while they recognized, they were no longer their spouse's primary caregiver, they still felt compelled to provide care for their partner (Torgé, 2020). As a result of the overwhelming urge to continue caregiving, spousal caregivers found themselves caught between caregiving responsibilities and respite (Torgé, 2020). In fact, within Sweden’s model of care, spousal caregivers are expected to aid in the care of their spouse, which can further complicate how staff view spousal caregivers and their relationship with them (Torgé, 2018, 2020). Indeed, it was found that care staff viewed the presence of spousal caregivers as a valuable resource that can complement their work, often dividing care tasks between them (Torgé, 2020). For example, “staff was responsible for help with medicine, hygiene, and feeding. Other daily activities such as shopping, cleaning, fetching meals, and taking walks were often done by spouses and thus ‘saved work’” (Torgé, 2020, p. 9). This structure of dividing care responsibilities was occasionally specified in the LTC home's formalized care plan (Torgé, 2020). Some spouses in the study further stated that it was apparent that their spouses “relied on them more than the staff, and they thereby filled an irreplaceable role in the care of their partner” (Torgé, 2020, p.7). This intense feeling of responsibility further relates to visiting spouses’ feelings of mistrust of LTC staff’s ability to provide adequate care for their partners (Torgé, 2020).

According to Torgé (2018), different municipalities can interoperate legislation and implement cohabitation decisions, directly impacting spousal caregivers' roles and the services/support permitted to them. To illustrate, Torgé (2018) found that homes can implement the legislation within two categories *'legitimate need'* and *'own right.'* Within the *legitimate need* perspective, "only individuals [with] the greatest need should receive the help offered in nursing homes. Conversely, they also hold that people who can still manage by themselves—such as coresident spouses—should not receive more help than they actually need" (e.g., spousal caregivers complete their own laundry and clean their own rooms) (Torgé, 2018, p. 51). Within this model, spousal caregivers are thus not on equal ground as their spouse and are viewed by staff as still caregivers rather than residents, despite the fact that many staff members wish to assist them (Torgé, 2018). However, the *own right* perspective gave the decision to receive services and care to the spousal caregiver as established through the payment of a care fee (Torgé, 2018). "A consequence of this is that the coresident spouse…is a resident on his or her own terms. The spouse's entitlement to care is not dependent on the extent of his or her needs" (Torgé, 2018, p. 53). Within this model, care staff incorporate the support of the coresident spouse into their care routines (Torgé, 2018). Spousal caregivers are therefore, viewed as a supportive feature in the care of their spouse (Torgé, 2018). Regardless, tensions between care staff and spousal caregivers were noted in both models, revealing that care staff routines were occasionally disrupted by spousal carers' claims over private rooms/apartments they shared with their spouses. For example, one staff member mentioned that conflicts could arise when furniture in the couple's apartment needed to be moved (sometimes without permission) for care purposes (e.g., space for equipment such as ceiling hoists), which could disrupt the spouse's attempt to create a "homelike atmosphere" (Torgé, 2020).

On the other hand, Hemingway et al., (2016), found that care staff view spouse's involvement and eventual frustrations towards them were a result of their own guilt for failing to uphold marital vows of caring for their partner. This perspective of staff was further demonstrated in the study to create friction as care staff expressed difficulty in their ability to connect with spouses as they struggled to accept their new role (loss of being a primary caregiver) and thus, find it challenging to work together (Hemingway et al., 2016, p. 881). This notion is "fuelled by the reality that within care facilities, staff are recognised as the primary caregivers and attributed power, legitimacy, and authority over the partner with dementia who is resident in the facility" (Hemingway et al., 2016, p. 881). Lastly, only four publications emphasized the systematic barriers that may inhibit a working relationship between spousal caregivers and care staff. Time constraints, high staff turnover, shift changes, and lack of funding and education were underscored in the literature to impede on quality of care and the development of constructive care staff and spousal caregiver relationships (Førsund, 2017; Hennings & Froggatt, 2019). Notably, these systematic barriers were acknowledged by both care staff and spousal caregivers (Hemingway et al., 2016, p. 886; Mullin et al., 2011).

Couples' Social Relationships. The community dynamics in LTC settings were revealed in seven publications to interfere with couples' capabilities to maintain their desired relationship quality. Although social engagement with other residents was shown to provide both spouses with the opportunity to form supportive friendships and companionship outside of the marital relationship, co-resident interactions and relationships were also shown to create difficult circumstances for the continuation of the marital relationship post-relocation (Kemp et al., 2016; Malone, 2016; Miller, 2016). Understanding couples' avenues of relocation to LTC settings, often stemming from an individual or collective decline in health, for couples' their synchronic relationship and desire to remain together form their experience of LTC (Kemp et al., 2016). Therefore, couples linked lives influence their social relationships within LTC settings as one partner's health status, and friendships can dictate the other's abilities/aspirations to interact with others (Gladstone, 1995a, 1995b; Kemp et al., 2016).

One article, in particular, by Kemp et al. (2016) examined the social lives of couples in AL when just one spouse relocated, or the couple relocated together. The results of this study highlighted the "interconnectedness of couples' lives, which was simultaneously beneficial and detrimental" in later life (Kemp et al., 2016, p. 851). To illustrate, couples who relocate together to LTC settings automatically have what the authors characterize as a "built-in companionship," which was determined to both be favoured as well as restrictive to the development of social relationships (Kemp et al., 2016, p. 842). Considering that social relationships between residents develop through program participation, meal seating arrangements, and staff involvement, for couples' who are interdependent such as when one spouse is caregiving for the other, this can hinder the caregiving spouse's ability to develop relationships with other residents (Gladstone, 1995a; Kemp et al., 2016). This notion aligns with the author's earlier works (Kemp, 2008), which discovered that AL's particular social dynamic of there being more women than men led wives to publicly demonstrate that their husbands are unavailable (e.g., handholding) (Kemp, 2008).

However, the comfortability in long-term companionship is sometimes favoured over more independence (Kemp et al., 2016). This finding coincides with the earlier works of Gladstone's (1995a, 1995b) studies which revealed that some couples who relocated together became more dependent on one other socially, while others experienced a sense of loneliness as one spouse grew more independent and developed stronger social relationships than the other. Furthermore, in some instances, one spouse developed frustration towards their partners as they desired more independence from their spouse as they felt obligated towards their spouse (Gladstone, 1995a, 1995b). By the same token, Hemmingway et al. (2016) found that some visiting spouses of persons with dementia felt as if they were “living separate lives” (p. 878). The authors found that spousal caregivers can feel disconnected from their partners everyday lives within the facility as their partner begins to socialize and develop new relationships (Hemingway et al., 2016).

Specific to couples where one spouse has dementia, the accessibility of having a dementia care unit (DCU) within AL enabled couples with different care needs to remain together (Kemp et al., 2016). However, the authors discovered that AL's social culture could inhibit asynchronous couple's ability to maintain their relationship (Kemp et al., 2016). Residents in AL were revealed to have little tolerance of persons with dementia, explaining that the needs of persons with dementia, particularly surrounding meals (e.g., food needing to be cut up and 'being messy eaters') were unsightly, and in one case, the AL "to accommodate other resident's preferences" restricted the persons with dementia abilities to eat in the AL dining room (Kemp et al., 2016, p. 846). These sorts of restrictions and attitudes ultimately left caregiving spouses to reduce their time spent in AL and spend more time in the DCU with their partners (Kemp et al., 2016). Therefore, limiting their abilities to obtain social relationships outside of their marital relationship. Lastly, it was explained that for persons with dementia having social engagement with other residents was shown to be a positive asset, especially if anything happens to their spouse and they are suddenly without them (Kemp et al., 2016). Having relationships outside of the marital relationship, therefore, can provide comfort at a time they “cannot remember why they are sad or do not recognize the loss” (Kemp et al., 2016, p. 852).

***Infidelity*.** Two publications highlighted situations in which married persons with dementia developed intimate relationships with other residents (Kemp et al., 2016; Miller, 2016). For example, articles mentioned instances where a visiting spouse found her husband holding hands with another resident. Another had her husband tell her that "he had a girlfriend" (Miller, 2016, p. 65). Both caregiving spouses in the articles recounted these experiences stating that they were initially shocked and felt a sense of heartbreak; however, they "described themselves as being pragmatic and open-minded, allowing for their ability to understand and accept the situations" as being part of having a spouse with dementia (Miller, 2016, p. 65). Interestingly, in Kemp et al.'s (2016) article where both spouses lived together in assisted living, two instances were illustrated where spouses of persons with dementia had found their partner in bed with another resident who also had dementia. Similar to Miller (2016), the instances were described as an upsetting and angering experience for the caregiving spouse (Kemp et al., 2016). These experiences were also highlighted to impact their social lives within the facility as their partner's infidelity were frequently gossiped about by other residents (Kemp et al., 2016).

Yet, it was mentioned that some caregiving spouses to persons with dementia struggle with the possibility or development of new intimate relationships while remaining married (Braithwaite, 2002; Førsund et al., 2015). For example, Førsund et al. (2015) study indicated that although "some of them expressed they would never think of getting involved with another as long as they were married, others admitted they were longing for someone to share their everyday life with" (p. 125). It was revealed that the loneliness involved in caregiving spouses' grief over the loss of their partners' cognitive capabilities could provoke some to seek new relationships and companionship (Førsund et al., 2015). Similarly, Braithwaite’s (2002), revealed that for caregiving spouses with relatively low couplehood, their marital vows were viewed as restrictive to their abilities to carry on with their lives.

Sexual Orientation**.** Only one article noted the experiences of LGBTQ+ couples. Although there is limited literature concerning LGBTQ+ couples' experiences in LTC settings, it is important to discuss the additional barriers and stigma faced by couples who identify as LGBTQ+ and how it impacts the preservation of their relationship post-relocation. Given the prejudice and discrimination that occurs in institutional settings, it is understood that many LGBTQ+ older adults feel the necessity to go 'back into the closet' when relocating to LTC settings (Malone, 2016). "Experiences may come in the form of homophobic or transphobic comments from staff or other residents, the lack of recognition that an individual of the same sex is one's life partner, and the failure to allow same-sex partners to make care decisions on a resident's behalf" (Malone, 2016, p. 45). There is a considerable amount of research on LGBTQ+ older adults' fears concerning LTC relocation, including the fear of inadequate care, staff neglect, and discrimination from other residents (Malone, 2016).

3.7. Physical Environment

The design and structure of LTC settings, were demonstrated in 20 publications to impact visiting spouses' abilities to interact with their partners as well as opportunities to maintain their relationship post-relocation. Although, there is limited literature that has explored how the physical environment of LTC enables persons with dementia and their partner to continue their desired relationship quality, two articles (Chapman & Carder, 2003; Cruz, 2006) address the barriers that impact family caregivers (with majority samples including spouses) and persons with dementia in specific. Importantly, in relation to place attachment and identity, two articles, Førsund and Ytrehus (2018) and Cruz, (2006) addressed the concept of ‘place making’ to describe the adjustment process and efforts made for persons with dementia when relocating to LTC. ‘Place making’ in this context signifies the means in which couples upon relocating collectively or a spouse to an LTC setting "create their own place and integrate themselves into the environment…by developing emotional attachment and maintaining familiar routines [to] transform unfamiliar spaces into places with personal meaning and opportunities for meaningful interactions" (Førsund & Ytrehus, 2018, p. 859). Given the task-focused and sterile atmosphere which often defines an institutional environment, the articles emphasized that for visiting spouses, the exercise of constructing a sense of place can be quite difficult as the environment offers limited autonomy over what is deemed public and private (Førsund & Ytrehus, 2018). Utilizing the concept of ‘place making’ to understand the many elements of the physical environment of LTC settings that influence couples’ abilities to construct a meaningful sense of place enables a deeper understanding of the physical environmental features in which inhibit couple’s sustainment of their relationship (Førsund & Ytrehus, 2018; Cruz, 2006). Two environmental features of LTC settings were highlighted in the literature to influence couples’ abilities to maintain their sense of couplehood and sense of place: ‘private bedrooms’ and ‘public spaces’ with the important subtheme of privacy.

Private Bedrooms. Private bedrooms were indicated as an important place for couples to continue their relationship (n=4). Private bedrooms provided opportunities for private interactions, perform familiar routines, and reminisce their shared history (Førsund & Ytrehus, 2018; Førsund et al., 2016). Two studies by the same author, Førsund et al., 2016 and Førsund & Ytrehus, 2018, mentioned how private bedrooms served as a space for the sustainment of couplehood. To illustrate, Førsund and Ytrehus (2018), who explored the parameters in which the LTC environment impacted visiting spouses' opportunities to interact with their partner, found that private bedrooms operated not only as a space of privacy but also embodied feelings of home and belonging. However, the transformability of private bedrooms into more of a 'homelike' atmosphere was demonstrated to be key in couples' use of the space (Førsund & Ytrehus, 2018). The authors discovered that couples appreciated the ability to decorate private bedrooms with objects from their home and collective past (e.g., photographs on the walls and other cherished items) (Førsund & Ytrehus, 2018). The ability to decorate in a 'homelike' manner with familiar objects was demonstrated to be essential to spark familiarity for persons with dementia and the continuity of marital relationships (Førsund & Ytrehus, 2018). It was found that familiar objects afforded conversation starters and reminiscence of their shared memories (Førsund & Ytrehus, 2018). However, it should be noted that the extent to which rooms could be personalized is limited and is contingent on variables such as policy and the presence of a roommate (Førsund and Ytrehus, 2018).

Similarly, Førsund et al.'s (2016) study, that explored the methods in which couples sustain their relationship post one partners with dementia's relocation to LTC, found that private bedrooms afforded a place for alone time and the ability to focus on the continuation of their relationship as a couple (Førsund et al., 2016). For example, the space served as a place to reminisce their shared history, practice familiar routines and activities (e.g., play cards, drink coffee, and look at photographs), as well as share intimate moments and display affection in privacy (e.g., hugs and kisses) (Førsund et al., 2016). Also, private rooms acted as a space for hosting other family members when they visited (Førsund & Ytrehus, 2018). Ultimately, revealing that private rooms can act as a homelike space that enables couples to express their relationship and shared lives (Førsund & Ytrehus, 2018; Førsund et al., 2016).

The design and structure of private bedrooms were further demonstrated to be significant environmental features in couples' opportunities to maintain their relationship (Chapman & Carder, 2003; Cruz, 2006; Førsund & Ytrehus, 2018). The size, dimensions, and furnishings of rooms were noted to facilitate, or hinder couples' use of the space (Chapman & Carder, 2003; Cruz, 2006; Førsund & Ytrehus, 2018). For example, larger rooms were preferred since they enabled better visitor seating options (Chapman & Carder, 2003; Cruz, 2006; Førsund & Ytrehus, 2018). Furthermore, it was expressed that the progression of a partner's dementia meant that room/furniture changes rendered it difficult to socialize in private bedrooms (Chapman & Carder, 2003; Cruz, 2006; Førsund & Ytrehus, 2018). Førsund and Ytrehus (2018) described how limited furniture and items such as hospital equipment (e.g., wheelchairs and hospital beds) and the need to remove home-like features made it difficult for couples to use the room as a place to have private conversations or 'entertain' other family members due to the limited seating capacity (Førsund & Ytrehus, 2018). Moreover, it was revealed that despite the efforts of personalization, that private bedrooms to spouses "will always be a 'sickroom' defined by the colours, sounds, sterile surfaces, and lighting that characterizes an institutional environment" (Førsund & Ytrehus, 2018, p. 859). This notion was also expressed by Cruz's (2006) study, which found that the lack of furniture and small dimensions of rooms often left family members to sit on the bed or stand when visiting, lending to shorter visits due to lack of comfort.

Privacy. Couples' opportunities to have private interactions were demonstrated in 13 publications to be an integral feature in their abilities to maintain their desired relationship quality. Importantly, challenges to couple’s privacy within LTC settings is strongly connected with the “inconsistent policies and practices surrounding the cohabitation of partner” (Malone, 2016, p. 30). The practice that prohibits couples with different needs of care to share a room challenges the capacity for private moments (Malone, 2016). Privacy appeared to be a crucial element in couples’ preservation of relationship particularly during the first phases of adjustment post relocation. This is noted to be a critical time period whereby spouses attempt to conserve shared routines and when interactions between partners may be more intensive (Førsund et al., 2016). The literature, however, conveyed a number of variables that challenge couples’ capacity to have private interactions (e.g., Chapman & Carder, 2003; Førsund et al., 2016; Kemp, 2008; Hunt, 2015). Most notable is the disturbance of care staff. The ongoing presence of care staff and frequent interruptions was revealed to not only cause tension but also limit couples' exchanges of private moments (e.g., Glasier, 2016; Glasier & Arbeau, 2019; Braithwaite, 2002; Hunt, 2015; Førsund et al., 2015, Førsund, 2017; Førsund & Ytrehus, 2018). Care staff were reported to enter rooms without notice and interrupt conversations and activities to provide care (Chapman & Carder, 2003; Førsund et al., 2016; Hunt, 2015; Kemp, 2008).

Interestingly, Førsund and Ytrehus's (2018) study noted that the feature of door locks, that may or may not be locked from the inside in some facilities. As a result, private bedrooms in this study were described as "only semi-private" as it was a common occurrence for care staff and at times other residents to enter their rooms (Førsund & Ytrehus, 2018, p. 870). Moreover, the sometimes-unavoidable component of roommates was also mentioned in four articles (e.g., Cruz 2006; Chapman & Carder, 2003; Hunt, 2015; Miskovski, 2017; Malone, 2016). Roommates create obvious challenges for privacy. Cruz's (2006) study as well as Malone (2016) express that a roommate's presence ultimately changes the dynamics of LTC as it creates additional challenges. For example, having a roommate limits the personalization of bedrooms, sentimental items and possessions can become stolen or damaged, opportunities for intimate moments are further reduced, and there is the added element of the roommate's family and them perhaps having a spouse of their own (Cruz, 2006; Malone, 2016; Miskovski, 2017). Malone (2016) notes that some found that have a roommate can be a positive experience that can provide friendship and companionship. Nevertheless, it was found that if roommates are present, family members will avoid spending time in their rooms due to fears of agitating their roommate (Cruz, 2006).

These dynamics related to privacy issues often result in challenges in opportunities for intimacy. Affection and sexual intimacy among older adults and especially among persons with dementia continue to be a sensitive and taboo topic within LTC settings (Malone, 2016). Nevertheless, intimacy is an important and meaningful element of a couple's relationship and was mentioned in 13 publications (Malone, 2016; Hunt, 2015). For example, Førsund et al., (2016) article found that although their partners progressing dementia altered the couple's intimate relationship before relocation to LTC, sharing intimate moments in privacy was an important element in the preservation of their relationship. For example, one participant in their study stated:

> *I always started the visits in her room. I showed up a little earlier when she'd had her afternoon nap, so that I got a few minutes with her in privacy. I wanted to give her a little kiss, hug her and say intimate things to her. Say how much I loved her and stuff like that. I only did that when we were alone* (p. 3019).

Notably, it was expressed that although private bedrooms afford some privacy, features of LTC settings such as its public nature, staff entering rooms without notice, and fears of judgment/scrutiny from care home staff and other residents made even the attempt for sexual intimacy challenging (Gladstone, 1995a; Hunt, 2015; Malone, 2016; Miskovski, 2017). Malone (2016) further revealed that some LTC settings have a "designated private space" for residents to use for more intimate moments; however, residents were reluctant to use such spaces due to fears of what staff and other residents may say (p. 304). Førsund et al., (2015) noted the varying feelings of spousal caregivers in their views of their partner in a sexual manner due to their partners' progressed dementia. This finding aligns with Alzheimer's Australia NSW (2017) publication, which noted the spousal caregivers' sorrow in losing the sexual aspect of their relationship. However, consistent with other publications, it was mentioned that the opportunity for physically intimate moments that are not necessarily sexual, such as cuddling in bed or giving a hug or a kiss, became something they deeply missed because of lack of privacy (Miskovski, 2017).

Finally, it is important to note that the progression of dementia was demonstrated to significantly affect both persons with dementia and their spouse's definition and ideas of privacy (Chapman & Carder, 2003; Cruz, 2006; Førsund & Ytrehus, 2018). Research reveals that both spouses need to redefine traditional means of privacy upon relocating to LTC (Chapman & Carder, 2003). Given that dementia changes an individual's understanding of privacy norms, research suggests that family members must modify their views of privacy as they adjust to and accept the idea of having other residents and staff handle personal possessions, care staff providing bodily care and the community atmosphere in which other residents may gossip and know personal information (Chapman & Carder, 2003; Glasier, 2016; Kemp et al., 2016).

Public spaces. Public spaces were primarily discussed in two articles as an important place for couples to connect (Chapman & Carder, 2003; Førsund & Ytrehus, 2018). Førsund and Ytrehus's (2018) article explains that the amount of seating available in public spaces such as activity spaces, family/living rooms, dining halls, and outdoor spaces played a substantial factor in their use, however, noting that limited seating provided little to no privacy. The researchers also mentioned how the furnishings, decorations, and overall atmosphere of the public places play a role in couples' use. Participants in this study emphasized the desire to have a homelike style and atmosphere that promoted social engagement, comfortability, and warmth (Førsund & Ytrehus, 2018). In the study, those facilities that promoted a more homelike atmosphere in their public spaces were utilized more, even if they lacked an amount of privacy (Førsund & Ytrehus, 2018).

Notably, the use of public spaces during visits was demonstrated in some cases to enable a sense of community (Førsund & Ytrehus, 2018). Some visiting spouses who regularly visited for an extended period expressed that public areas provided (largely unavoidable) opportunities to interact with care staff and other residents, resulting in positive relationships (Førsund & Ytrehus, 2018). At the same time, many visiting spouses expressed feelings of alienation due to other resident's health status and declining cognition (Førsund & Ytrehus, 2018). This sentiment was also expressed by Tilse (1994) which explained that privacy can invoke feelings of isolation for some visiting spouses. The author found that as their loved one's dementia progressed and may not be as interactive, having visits in public spaces was preferred as seeking privacy can restrict visiting spouses "can limit opportunities for social contact, consultation with staff, support for themselves and participation in the daily life of the facility" (Tilse, 1994). These findings align with Chapman and Carder's (2003) article, which touched on the use of public spaces by family caregivers. The authors revealed that public spaces were used for visits "because visitors tended to visit with their family member wherever they found him or her within the facility" (Chapman & Carder, 2003, p. 518). Like Førsund and Ytrehus's (2018) article, the authors found that the utilization of public spaces afforded opportunities for social engagement with other residents and care staff, which proved beneficial for visiting family members. Interestingly, the authors highlighted the use of outdoor spaces (when weather permits) for visiting and private moments (Chapman & Carder, 2003).

3.8. Relevance of the Findings for Future Research and Development of a Grant Proposal

This scoping review offered valuable insights into the circumstances that affect a couples' experiences and abilities to maintain their relationship within the LTC environment. Key findings emphasize the importance of older couples' desires to continue their relationship in LTC, validating previous research findings of the importance of couples' abilities to maintain their sense of couplehood as an essential aspect of couples' health and quality of life when one spouse has dementia (e.g., Førsund & Ytrehus, 2018; Hemingway et al., 2016; Hennings et al., 2013). The presented themes demonstrated the complex and overwhelming emotional experience connected with involuntary separation and perceptiveness into the culture of care that impacts couples' abilities to sustain their relationship post-relocation. Notably, the perspectives and experiences portrayed are not representative of all couples. Indeed, it is vital to recognise that some couples may actually welcome, seek, or benefit from the separation for various reasons (e.g., to reduce some of the emotional strain in seeing their spouse regularly, alleviate caregiver burden, etc.).

Furthermore, the literature provided insight into the conditions that contribute to spousal caregivers' loss of couplehood with their partners. In particular, the review highlighted the compounding losses associated with having a spouse with dementia and the impacts of physical separation (e.g., Hunt, 2015; Høgsnes et al., 2013; Førsund et al., 2015; Miller, 2016; Watterson, 2017; Glasier & Arbeau, 2019). These losses were further demonstrated to have deleterious consequences on the health and well-being of spousal caregivers. Spousal caregivers experienced depression and grief, mourning the prevailing sensation of losing their shared life with their partner (i.e., shared daily routines, relationship identity, and a shared future) (Førsund, 2017; Førsund et al., 2015; Hennings et al., 2013; Mullin et al., 2011). Similarly, spousal caregivers could experience stress and anxiety towards the future of their partners' deteriorating health status, their partner's well-being, and the quality of care provided in their absence (Hunt, 2015). Comparatively, one study noted that persons living with dementia experience a significant loss of identity as the disease progresses and the changes in their relationship with their spouse (Miskovski, 2017). It was revealed that the dynamics of their relationship change when their spouse transitions into a caregiving role; for example, persons with dementia can feel like a burden to their spouse and expressed that their spouse will talk down to them.

Understanding the emotional consequences, routinely visiting provided opportunities to continue aspects of their relationship, enabling opportunities for intimate moments, reminisce, and participate in activities together (Førsund et al., 2016). Visiting also provided opportunities to check on their partners' care and advocate for changes (Miller, 2016; Mullin et al., 2011; Sandberg et al., 2001). In effect, it was found that spousal caregivers can have challenging relationships with care staff (Braithwaite, 2002). Additionally, the physical environment was illustrated to impact the opportunities for visiting spouses to interact with their partners (Førsund & Ytrehus, 2018). In particular, the notion of 'place-making' meaning couple's ability to create a meaningful place to connect is revealed in the literature as challenging because of lack of privacy and institutional design/practices (e.g., roommates, care staff interruptions, and communal spaces) of LTC settings (Førsund & Ytrehus, 2018; Heliker & Scholler-Jaquish, 2006). The identified obstacles faced by visiting spousal caregivers in maintaining their sense of couplehood and the implications of involuntary separation provide a valuable glimpse into the unique experiences of married couples in LTC settings.

The results of the review highlight several important directions for future research. First, the literature failed to address the current issue of involuntary separation of married couples in LTC when one spouse has dementia and requires more complex care, and how this affects couples' ability to maintain their relationship. Second, many studies focused exclusively on the perspectives of spousal caregivers rather than exploring the experiences of both (i.e., the caregiving spouse and the spouse with dementia). Omitting people living with dementia negates the perspectives and opinions of a significant percentage of the population in LTC and the relevance and value of spousal relationships in the lives of many persons living with dementia. Given that little is known about the experiences of both spouses', inquiry into the experiences and perceptions of persons with dementia will further help to develop our conceptual understanding of couplehood in LTC settings and provide valuable insight into the experience and impacts of separation and loss of relationship quality on a couple as a unit. Therefore, completing interviews with both spouses is deemed an appropriate and valuable method to gain a comprehensive understanding of the phenomena of couplehood in the LTC settings and the challenges couples may face in preserving their desired relationship quality post-relocation. Moreover, investigating the experiences of persons with dementia will provide useful information for improving person-centred practices and education.

Third, the literature demonstrated that care staff often do not understand the role of spousal relationships and couplehood. There is a paucity of literature that showcases the viewpoints of care staff in terms of their understandings of the significance of couplehood and the potential barriers they may face (e.g., policy, education, time constraints) in their abilities to provide space for the continuity of spousal relationships within the LTC environment. Additionally, there is a scarcity of research that examines how the physical design and structure of LTC settings inhibit couples' opportunities to interact meaningfully. Supplementing resident couples' interviews with the perspectives of care staff through focus groups can provide a more holistic understanding of LTC settings' socio-physical environment (e.g., meal seating arrangements and the distance between units) and the culture of care that impacts older couples' abilities to maintain desired aspects of their relationship post-relocation. Furthermore, offering vital insight into how or if LTC settings have been transformed (e.g., care practises and physical design) to accommodate married couples under B.C.'s new policy guideline.

Finally, studies tended to focus on middle to higher socioeconomic status (SES) couples predominantly Caucasian. Therefore, there is a lack of research that acknowledges the respective experiences of older couples within more marginalized populations, such as the LBGTQ+ community, immigrants, indigenous populations, and those of different racial/ethnic backgrounds. As a result, presenting a gap in knowledge about the influence of cultural values within couplehood and additional barriers resulting from discrimination. By defining marriage within the Family Law Act of B.C., in which common-law relationships and non-heterosexual marriages/relationships are included, the sample of resident couples is intended to be inclusive and productive of a diverse sample. Furthermore, in completing the proposed study in the highly culturally diverse region of Metro Vancouver, it is important that racial/ethnic heterogeneity be reflected in a study's sample. The data gained from the proposed study will be beneficial in the development of systematic changes, effective policy initiatives, and practice frameworks that can support a more flexible model of care that ensures that older couples in B.C have a place within the structure of LTC settings, that will enable them to remain together for this next chapter of their lives.

3.9. Policy and Practice Implications

The review indicated that the socio-physical environment of LTC can significantly impact a couple's opportunities to engage with one another meaningfully. In particular, couples' ability to transform spaces into places of significance, such as the personalization of private bedrooms and opportunities to maintain shared routines, was demonstrated as an essential feature in the maintenance of couplehood (Førsund & Ytrehus, 2018). LTC homes that created a welcoming environment for visiting spouses, such as providing chairs in private spaces (e.g., bedrooms), were demonstrated to signify that family members are welcome and encouraged to use the area during their visits (Førsund & Ytrehus, 2018). Similarly, it is suggested that in common areas, which was demonstrated to be an opportunistic space for couples to connect, particularly when their spouse's dementia has progressed significantly, that homes provide ample seating that allows for some privacy while remaining connected to staff and other residents.

Additionally, it was suggested that LTC homes provide arrangements for spouses who wish to enjoy meals with their partners to better accommodate and maintain couples' shared routines. (e.g., additional seating and meals), as well as include visiting spouses in care home activities (e.g., exercise programs, art classes, concerts/events, etc.) (Hemingway et al., 2016; Hunt, 2015). Hunt (2015) found that couples who were able to remain sharing meals together had lower weight loss/malnutrition rates and decreased symptoms of depression. Similarly, for those separated between facilities, that transportation services should be made available for spousal caregivers (Glasier & Arbeau, 2019). Providing transportation between facilities is said to be provided as part of B.C's policy to support couples that could not be accommodated in the same facility (e.g., one in LTC the other in AL/IL) (Government of British Columbia, 2016). However, like mentioned above, the provision of this service is yet to be determined.

Other recommendations involve having care staff gain a better understanding of their resident's life history, such as through having staff perform a more in-depth admissions interview that concentrates on relationships and having that information be made readily available (e.g., wedding anniversary, children, memorable trips or experiences, shared routines, etc.) (Hemingway et al., 2016). Having care staff know this information will not only help improve care but also may "aid spousal caregivers in upholding positive illusions of marriage and their spouse" (Hemingway et al., 2016, p. 887). Likewise, in recognition of the systemic concerns such as "lack of staff time, frequent staffing changes, financial/resource challenges, transportation issues, among others," it is recommended that pressure be put on governing bodies for culture change in LTC (Hemingway et al., 2016, p. 887). Lastly, acknowledging spousal caregivers' experiences of grief and ambiguous loss, it is recommended that support services such as counselling or grief groups be afforded (Hemingway et al., 2016; Sandberg et al., 2001; Torgé, 2018).

In addition, research that is longitudinal in design that will enable the assessment of changes over an extended period, such as in the context of dementia progression, would be valuable. This would allow for the study of dyadic relational changes in LTC over time, as well as the identification of some of the causes of these changes. Likewise, ethnographic research that affords observational data of spousal relationships in LTC, interactions between care staff and residents, and the physical design of LTC can provide useful information on the socio-physical environmental barriers that perhaps challenge the continuity of marital relationships in LTC (Funk & Stajduhar, 2009).

As previously stated, B.C.'s policy allowing couples to live together in LTC is novel and therefore, it is unclear whether it has been implemented, and the practical implications have yet to be evaluated. However, Sweden's "Cohabitation Guarantee" legislation implemented in 2012 arguably provides a useful framework for applying B.C’s policy and provides valuable insight into the practicalities and potential issues. Like B.C’s policy, the "Cohabitation Guarantee" permits couples to live together in LTC, despite only one spouse fitting the care requirements, such as living with dementia (Torgé, 2018). This model of care is now common practice, with LTC homes modifying spatial design to accommodate couples, such as having adjoined private rooms and enhancing larger single rooms to accommodate two beds and closets (Armstrong & Braedley, 2016). In addition, as mentioned previously, the legislation permitted a more flexible care model in which space was created for spousal caregivers to continue to participate in their partner's care (e.g., dressing and feeding during mealtimes) and maintain shared routines (Armstrong & Braedley, 2016). For example, having routines such as eating meals in their own apartments or having their spouse dress them was not only permitted but written in formal documents such as care plans (Torgé, 2020). This model, however, was demonstrated to have both positive and negative attributes for spousal caregivers.

As discussed above, Torgé (2018) evaluated the practical implementation of this legislation within the context of couples' lives in LTC and the needs and rights of spousal caregivers. As a result of the legislation's vagueness, "municipalities are free to decide on specific guidelines on its implementation, such as tenant contracts" (Torgé, 2018, p. 48). Therefore, issues such as rooms/apartments' availability and the features of spousal caregivers' rights can come into play (Torgé, 2018). For example, the study revealed that within the two participating homes, each home has different viewpoints regarding the role of spousal caregivers in LTC characterized as *"legitimate need"* and *"own right"* (Torgé, 2018). Interestingly, these viewpoints were discovered to originate from executive directors and board opinions, which are then believed to be transmitted down to care staff. These differing perspectives dictate how spousal caregivers are integrated into the home's socio-cultural environment, as well as the types of care and services they can be provided (e.g., as a caregiver there for their spouse, or as a co-resident who is also entitled to services and care), as described in Chapter 3 (Torgé, 2018).

Sweden's "Cohabitation Guarantee" legislation lends important implications for the execution of B.C’s policy in practice and poses questions, such as how each LTC home might interpret the policy, how couples will be accommodated (e.g., enough beds or rooms, large enough rooms to house both spouses), and if the admission of a spousal caregiver can impact the waitlist/availability of care to someone who requires LTC and is single? Regardless, as demonstrated in Sweden’s legislation, it is possible to create a more flexible model of care and as can be seen in the “own right” perspective, a culture of care that views couple’s health and well-being as a unit.

In addition to policy adjustments, there is an explicit need for more innovation with regard to our provincial approach to LTC. Both nationally and internationally, some governments are concentrating their efforts towards the development and implementation of novel and integrative methods to senior’s care and person-centered/directed (PCC) approaches. Drawing from these ideas and initiatives can provide novel solutions that can re-design the structure of LTC and enable older couples in B.C. to age together in a system of care that suits both their individual and collective needs. One promising example and alternative that affords accommodation for couples with different care needs is the Group Homes Australia Model. This model of care is structured around having homes “on ordinary suburban streets…where 6 to 10 residents live together [providing] 24-hour support including dementia care, palliative and respite care” (Aged Care Online, n.d., sec. About Us). This model is founded on the notion of maintaining a home-like environment and focusing on maintaining individuals’ sense of independence and abilities (Aged Care Online, n.d.).

Within this model, care plans and initiatives are developed to support each spouses’ individual care needs as well as support the continuity of their relationship. Couples, for example, can choose between sharing a room and having separate rooms within the same home. Furthermore, concentrating on providing respite from caregiving duties for the caregiving spouse, and preserving couples' shared routines (e.g., eating meals together or having coffee at their preferred dining place) (Aged Care Online, 2017). This model, which aligns with contemporary PCC and culture change movements and offers appropriate space for the continuity of spousal relationships, represents an interesting and beneficial alternative to B.C.’s present structure of LTC for couples.

It is worth reiterating that some couples may benefit and want the separation from their spouse for various reasons (e.g., caregiver burden, emotional difficulty in seeing their partners decline, etc.). Considering models such as campuses of care, which have gained popularity worldwide as well as other provinces, can offer the necessary care for each spouse and ability to maintain their desired relationship quality within a chosen degree of distance. To illustrate, campuses of care offer different levels of care within a single community (e.g., IL, AL, and LTC) (Morton-Chang et al., 2021). This design, therefore, assures that visits are easy, and that meals and activities can be shared if desired. Although, campuses of care have existed in various forms for some years in B.C and in Canada, this community model is limited within various parts of the province and there are questions regarding distance, frequency of visits, access to services (e.g., transportation) and policy in regarding to COVID-19 safety protocols. Nevertheless, this model can benefit couples within various circumstances, such as when couples' care needs are so diversified that for spousal caregivers, moving into LTC would be too much of a sacrifice (such as in cases where their spouse has early-onset in their 50's). In relation with the above, it is evident that B.C needs to focus on innovation and integrative approaches to LTC, to support couples needs with dignity as their unique circumstances and care needs change and evolve.

Chapter 4.

Methods for Simulated Grant Proposal

This chapter presents the study design, research setting and ethical considerations of the simulated research proposal for CIHR. The proposed study will draw from, and build upon, the scoping review findings presented in Chapter 3. The identified themes from the scoping review and knowledge gaps have guided the development of interview guides for both resident couples and care staff focus groups.

This study will be guided by two overarching research questions with five sub-questions:

- **Research Question 1:** How does the current practice of separating married couples between LTC settings (including AL and IL) when one spouse is living with dementia and resides in LTC impact the marital relationship and couples' abilities to sustain couplehood?
    - **Sub-Question:** What are the challenges couples face in maintaining couplehood?
    - **Sub-Question:** What are the mental and physical health effects both individuals may face when separated in LTC settings? (e.g., responsive behaviors in persons with dementia, depression, anxiety, malnutrition).
- **Research Question 2:** How does the LTC socio-physical environment influence couples' opportunities to maintain their relationship?
    - **Sub-Question:** What is the understanding of care home staff (e.g., nurses, care-aids, directors of care, and executives) of couples' needs in LTC?
    - **Sub-Question:** What policies and care practices act as barriers in couples' capacity to maintain the desired aspects of their relationship in the LTC environment?
    - **Sub-Question:** What physical environmental features of the LTC setting inhibit couples' capacities to interact meaningfully? (e.g., locked units, locks on private bedroom doors, distance between units, lack of privacy).

4.1. Research Design

The study will adopt a qualitative research method design consisting of two components: semi-structured interviews with resident couples and focus groups with LTC care staff. Applying a data triangulation approach that involves utilizing two methods of qualitative inquiry is beneficial for increasing validity, attaining more comprehensive data, and gaining a better understanding of the phenomenon under investigation (Lambert & Loiselle, 2008; Perlesz & Lindsay, 2003). Combining the perspectives of resident couple interviews with care staff focus groups will afford a deeper and more comprehensive investigation of the subjective experiences of older couples and the care practices in LTC settings that challenge couples' abilities to maintain their desired level of relationship. In addition, the two levels of understanding gained will warrant the identification of convergent and divergent data that may not have been discovered if only one method were conducted (Carter et al., 2014; Farquhar & Michels, 2016). In parallel, the potential for diverse and complementary findings will further provide richer insight and a more nuanced and comprehensive examination of this complex topic (Funk & Stajduhar, 2009; Lambert & Loiselle, 2008).

The two methods will be used in a complementary way in which focus groups with staff will be conducted in a subsequent phase after completing resident couple interviews. The emergent themes from the semi-interviews with the resident couple will inform the topics and questions addressed in the focus groups with care staff. In the first phase, face-to-face semi-structured interviews will be conducted with 10-12 couples at multiple LTC or Assisted/Independent Living facilities (AL/IL) (one spouse living in LTC and the other living in a different LTC or in an AL/IL) in Metro Vancouver, B.C. In recognition of the gap in knowledge surrounding the impacts and subjective experiences of involuntary spousal separation on persons living with dementia, interviews will be completed with both spouses, including those with dementia. This will result in a total of 20-24 interviews. These interviews will be used to gain insight into older couples' lived experiences separated in LTC settings and how their separation and potential loss of couplehood has impacted each spouses' health and well-being.

Research with persons with dementia is minimal due to the challenges presented by the nature of the disease and progressive cognitive decline that deem persons with dementia "as incapable of verbally communicating their thoughts and feelings" (Hubbard et al., 2003, p. 351). However, since the 1990s, research has challenged this assumption (e.g., Kitwood, 1997) affirming that a person with dementia "has a sense of self, personality, thoughts, and feelings [and] can actively contribute to research studies" (Cridland et al., 2016; Hubbard et al., 2003, p. 351). Indeed, the inclusion of persons with dementia's perspectives and experiences is critical in this study as it is imperative to understand how separation from a spouse in LTC settings impacts their health, well-being, and overall quality of life.

The collaborative and flexible nature of semi-structured interviews has been demonstrated in research as an appropriate and valuable method to gain insight into persons with dementia's perspectives and experiences (Cridland et al., 2016; Mazaheri et al., 2013). For example, semi-structured interviews enable the development and use of an interview guide with specific questions/topics to be covered; however, the interviewer can diverge from the guide when deemed appropriate to follow the topical trajectories of the interview (Hesse-Biber & Leavy, 2006). This interview structure allows for a more genuine conversation, offering participants the opportunity to digress into topics and ideas that the researcher may not have anticipated (Hesse-Biber & Leavy, 2006). This flexibility further allows the interviewer to respond and inquire about emergent topics of importance (Hesse-Biber & Leavy, 2006).

The second phase involves conducting focus groups with LTC home care staff. Specifically, these focus groups will comprise of nurses and personal support workers from the participating Metro Vancouver LTC homes in which the spouse with dementia resides. Each focus group will consist of 5-7 care staff, with one session conducted per participating site. Questions will be open-ended with the intent to promote discussion (Nagle & Williams, 2020). Focus groups were chosen for this study over other methodologies since they allow individuals' understandings and interpretations to be heard and explored. Simultaneously, the group dialogue can stimulate and encourages a more dynamic and collective viewpoint and discussion and debate on a complex and under-researched topic (Nyumba et al., 2017). As such, focus groups can allow participants to share and collaboratively co-create synergistic viewpoints and understandings (Nyumba et al., 2017). In comparison to other methodologies such as surveys, these data can better provide "insight into social relations. Moreover, the information obtained can reflect the socially constructed nature of knowledge better than a summation of individual narratives" (Nyumba et al., 2017, p. 28). Considering this point, focus groups will be beneficial to achieve a comprehensive understanding of care staff's experiences and perceptions in providing care and space for older couples in LTC settings. They are also useful for better understanding perspectives on the socio-physio environmental features of LTC settings' (e.g., the culture of care, intuitional protocols, and practices) that can challenge couples' abilities to maintain their relationship. Focus groups are also valuable for gaining an in-depth understanding of many relevant applied or practical issues (e.g., ideas for interventions and effective knowledge translation strategies).

In addition, the data gained from the focus groups will provide a complementary perspective into the impacts of separation on persons with dementia, such as perhaps changes in their mood/behaviours when alone or with their spouse, that may not have been revealed in interviews. Also, in the context of data triangulation, focus groups in this study will be integral to support or refute data gathered through resident interviews. Drafts of the interview guides for both resident couples and care staff focus groups have been developed. As previously mentioned in the chapter introduction, the interview guides are based on the scoping review's identified themes and knowledge gaps (Refer to Appendices). Furthermore, because focus groups will be completed after resident interviews, emergent interview findings will guide the covered questions and topics, and thus, their interview guide will be modified as appropriate.

4.2. Research Setting

This study will involve multiple LTC homes and AL/IL facilities in Metro Vancouver, B.C., located in the Vancouver Coastal Health (VCH) and Fraser Health Authorities (FHA). The LTC homes and AL/IL facilities will be selected based on availability of access for the researcher team and presence of married couples who fit the inclusion criteria. This identification process will be conducted in close consultation with leadership team in LTCs/ALs/ILs at VCH and FHA. The inclusion of different LTC homes and AL/IL facilities will also allow for the exploration of potential variations in organizational culture, policy, and practice. Focus groups with LTC staff will be completed at the LTC homes or at convenient community settings.

4.3. Sampling and Recruitment

Both resident couples and care staff participants in the selected homes will be recruited with the support of identified LTC homes' executive directors and AL/IL administration. The leadership members at selected sites will be contacted via email or telephone to determine if couples in their homes fit the study's interest and inclusion criteria, which will be explained below. Once executive directors/administrators have consented to their LTC/AL/IL to partake in the study, they will identify care home staff that will help select resident couples who fit the inclusion criteria and would be interested in participating. The identified care staff will also act as a liaison between myself, research assistants and the couples.

Resident Couples

The 10-12 couples participating in this study will be recruited using the purposeful sampling technique of criterion sampling (Patton, 2015). Inclusion criteria for the spousal caregiver include: (i) having each participant fluent in English, (ii) partner in a long-standing committed and/or marital relationship, (iii) residing in an LTC home or AL/IL facility, (iv) having a spouse with dementia living in a care home, and (v) being involuntarily separated from their spouse because of their spouses' care needs. Inclusion criteria for persons with dementia include: (i) English speaking, (ii) having a previous diagnosis of some type of dementia (e.g., Alzheimer's disease or vascular dementia), (iii) having enough language and communication ability to participate (e.g., having a cognitive performance scale number as being 1 = borderline intact (MMSE score of 22) to 2 = mild impairment (MMSE score of 19), or potentially 3= moderate impairment (MMSE score of 15), however, interview questions would need to be further adjusted), (iv) the ability to give consent, and (v) voluntarily wanting to participate and share their experiences. The selection of persons with dementia and determination of eligibility will be completed with the input of care staff. The determination of persons with dementia participants' capacity to provide consent is explained in detail below.

Furthermore, eligible participants will be selected not only from the inclusion criteria stated above, but with consideration to participant interest and couples' circumstances (e.g., life history/story and situation within the LTC home or AL/IL). As mentioned previously, the definition of marriage aligns with the Family Law Act of B.C., which includes both common-law relationships and non-heterosexual relationships

(LGBTQ+) (Family Law Act 2011). Thus, participants' relationships included in this study will not solely be based on legal recognition, but couples committed and shared emotional attachments and experiences (Braithwaite, 2002; Walker & Luszcz, 2009).

Care Staff

Focus group participants will include nurses and direct care staff (personal support workers) from LTC homes in which the spouse with dementia resides. LTC home care staff were selected to gain perspective into the organizational culture and socio-physical environment of LTC that can impact couples' abilities to meaningfully interact. LTC home care staff furthermore will provide a complementary perspective into the impacts of separation on persons with dementia, such as perhaps changes in their mood/behaviours when alone or with their spouse. LTC home care staff will be recruited through purposeful sampling and include care staff who are often in contact with the identified married residents (Palinkas et al., 2015). The recruitment poster is shown in Appendix J, will also be placed within the homes. Focus group inclusion criteria will involve having each staff member be English speaking, be either a nurse (i.e., registered nurse (RN) or licensed practical nurse (LPN)) or personal support worker working within the LTC setting of the spouse with dementia.

4.4. Ethical Considerations and Informed Consent

Ethics approval will be granted from both the Simon Fraser University Research Ethics Board and the health authorities of VCH and FHA. Both spouses and all focus group participants will be required to sign a written consent form. The consent form will describe the study's purpose, their participation, and detail participant confidentiality. The form will also explain the participant's abilities to withdraw from the study at any point in time. The informed consent forms can be found in Appendices E, F & G.

To safeguard persons with dementia vulnerabilities, there are important ethical considerations when including persons with dementia in research. A principal concern is the participants' ability to provide informed consent (Howe, 2012). Although persons with dementia have been characteristically left out of research due to compromised decision-making abilities and fears of abuse and exploitation, recent research has found that "persons living with dementia have a sense preference and values and be capable of expressing their views" (Canadain Centre for Elder Law, 2019, p. 59). Informed consent is described as an autonomous decision by a person deemed competent to sanction their research participation (Lepore et al., 2017). Persons with dementia participants' capacity to consent "depends on whether he or she can communicate relatively consistently, understand basic information about choices, evaluate the implications of different choices, and rationally comprehend the risks and benefits associated with different options" (Lepore et al., 2017, p. 3). Furthermore, research suggests that understanding at an emotional level what they are consenting to is also an important aspect (Howe, 2012). Thus, measures such as the Cognitive performance scale or the Mini-mental status exam (MMSE) are not solely considered adequate to justify whether a person with dementia can give consent (Howe, 2012).

In consideration of the above issues, the principles of the process consent method will be applied (Dewing, 2007, 2008). As explained by Dewing (2007, 2008), there are five aspects of process consent which views consent as an ongoing process, practices assent, and respects the decisions of dissent from participants: (1) Background and preparation (2) Establishing a basis for capacity and other abilities (3) Initial consent (4) Ongoing consent monitoring (5) Feedback and support (Dewing 2008). First, permission will be gained from the care staff and the participant's spouse to access the person and gain biographical information (Dewing, 2008). Notably, this access does not imply proxy consent (Dewing, 2008). It does, however, acknowledge the "role of various gatekeepers and… enables persons deemed meaningful by the person with dementia and/or authorized representatives to be included in the process" (Dewing, 2008, p. 62). Members of the research team will visit participants before gaining consent to form a trusting relationship with participants and observe/understand participants' personalities (Dewing, 2007). Gaining descriptions of non-verbal cues such as facial expressions and overall demeanour can aid in the ability to evaluate ongoing consent (Dewing, 2007, 2008).

Secondly, understanding the limitations of numerical scores from assessments such as the Cognitive performance scale or MMSE, establishing a basis for capacity and other abilities involves the researcher's own assessments of the eligibility of participants (Dewing, 2008). The research team will utilize their knowledge and understanding of participants in consideration to a "significantly less emphasis on the person's ability to retain information and appreciate consequences and more on how it feels to the person in broad terms" (Dewing, 2008, p. 62). Thus, participants' consent will be continuously evaluated and examined by the research team who will note any decisive behaviour that may demonstrate the persons' desire to dissent (Dewing, 2008). Thirdly, initial consent as described by Dewing (2007, 2008), moves away from traditional conceptualizations of consent, and will involve providing information to participants in a manner that respects their "abilities and preferred ways of receiving information" (Dewing, 2008, p. 63). Initial consent will be gained through both verbal consent and adapted written consent forms (Dewing, 2007, p. 19). In addition, in cases where the person is deemed unable to provide informed consent, their spouse (or if another person is legally recognized such as an adult child) will act as their substitute decision maker and will provide consent and sign their consent form on their behalf (Dewing, 2008; Lepore et al., 2017).

Within the consent form, participants will be given the option to permit researchers to video record interviews. Audio recordings will further be offered as an alternative option. Detailed notes will be taken during the interviews concerning the participant's body language and non-verbal cues to understand how consent is given in the person with dementia's everyday life (Dewing, 2007). Additionally, ongoing consent monitoring, involves the continuous assessment of consent throughout the interview process (Dewing, 2007, 2008). Participants will be reminded about the purpose of the research as well as their rights to withdraw from the study if they wish, and will be monitored for any signs of verbal and non-verbal dissent or desires to withdraw (Dewing, 2007, 2008).

Lastly, the fifth element of feedback and support encourages key stakeholders' involvement and feedback if issues or concerns arise in the field and during the interview process (Dewing, 2007, 2008). The research assistants will first notify me with any concerns. I will then solicit feedback and other necessary involvement of care staff, my research supervisor, or the participant's spouse to help resolve the issue (Dewing, 2007, 2008). Additionally, spouses and care staff will be given contact information (phone number or email address) to inform the research team if there are any changes in the person with dementia because of the research before resuming the interview process (Dewing, 2007). Dewing (2007) also notes that researchers should consider the person with dementia’s abilities to transition back into their daily routines from the research context. The aid of care staff members will be enlisted when the interview sessions are completed to help the person with dementia transition back into their daily routines and note the interventions needed. Finally, in situations where it becomes necessary to express to care staff specific concerns from the participant, I will first ask permission from the participant to bring forth their concerns and do so while respecting confidentiality (Dewing, 2007).

4.5. Data Collection

With the assistance of two trained research assistants, I will conduct both the semi-structured interviews with resident couples and care staff focus groups. To uphold confidentiality, interviews with the resident couples will be completed in either a participant's private bedroom or in an allocated private space within the facility that can be utilized with permission (e.g., conference rooms, family visiting rooms). Interview times with resident couples will be coordinated around the care home's routines (e.g., meals and activities), caregiving duties, and personal appointments. Interviews will last approximately 60 to 90 minutes per participant. Interview guides for both spousal caregivers and persons with dementia have been developed and can be found in Appendices B and C. Interview guides are "a set of topical areas and questions that the interviewer brings to the interview" (Hesse-Biber & Leavy, 2006, p. 126). The use of an interview guide ensures the discussion of each identified key themes and/or topics (Hesse-Biber & Leavy, 2006; Patton, 2015). The interview guides are based on the study's research questions and build upon the identified themes and relevant research gaps from the scoping review. In addition to notes taken during the interviews, interviews with both spouses will be recorded via tape recorder to ensure confidentiality. Having audio recordings of each interview is imperative since it ensures that interviewees' responses are accurately represented and that comprehensive data is collected (Charmaz, 2006; Patton, 2015).

Conversational Interviews with Residents with Dementia

There are several pragmatic elements to consider when conducting interviews with persons living with dementia (Cridland et al., 2016; Quinn, 2017). Firstly, interviews need to be conducted in an environment with minimal distractions, which can be difficult in a care home setting (Quinn, 2017). A person’s place of residence has often been chosen to interview persons with dementia as they “prom[ote] familiarity for participants; ga[in] insight into the life of people with dementia; and having environmental cues which may facilitate the interview” (Cridland et al., 2016, p. 11). In consideration of this study’s inquiry into the sustainment of couplehood within the boundaries of the LTC environment, completing the interview in the persons, private bedroom can not only provide the quiet/private place to complete the interview but further aid in the promotion of recall or reminiscence and the identification of important issues (Cridland et al., 2016, p. 11).

Secondly, in respect to the wide range of persons living with dementia's needs, interviews need to be scheduled "at an appropriate time of day for participants (e.g., avoiding late afternoon interviews when participants may be tired and/or considering the impact of medication)" and must factor in the person's feelings day by day (e.g., if they are not having a great day) (Cridland et al., 2016, p. 11; Quinn, 2017). Thus, care staff will be contacted before completing the interview to find the best time (e.g., in consideration to medications, activities/programming, and mealtimes) and to assess how participants may be feeling and if they would be interested in participating that day (Cridland et al., 2016; Harman & Clare, 2006; Quinn, 2017). Moreover, it is advised that interviewers develop a rapport with persons with dementia participants before interviewing them to build trust and develop a level of familiarity (Alzheimer’s Society, 2020; Harman & Clare, 2006). Thus, interviewers will allocate extra time before the interview to facilitate a less formal conversation and build rapport (Cridland et al., 2016; Quinn, 2017).

Lastly, it is suggested that interviewers understand the progression of dementia and know of supportive communication strategies (Cridland et al., 2016). For example, interviewers must allow space for larger amounts of time for participants to answer questions, must be able to rephrase questions if the person looks confused, and must be aware of participants’ body language throughout the interview, to not only note when the person may need to take a break but also to practice ongoing consent (Quinn, 2017). Therefore, research assistants must have the appropriate personality characteristics (e.g., patience, empathy, friendly and open demeanour etc.) and be required to refer to journal articles and other resources before interviewing to ensure sensitivity to interview pace and characteristics of dementia (Brinkmann, 2007).

Conversational Interview Guide Development for Residents with Dementia

There are multiple considerations when developing an appropriate interview guide for persons with dementia (Alzheimer’s Society, 2020; Cridland et al., 2016; Quinn, 2017). Key recommendations involve including an introductory statement at the beginning of the interview with the intent to have the interviewer introduce themselves, reiterate the interview's focus, and outline what will occur during and after the interview (Alzheimer’s Society, 2020). Furthermore, the interview's focus is reiterated when needed (Alzheimer’s Society, 2020; Cridland et al., 2016). It is also advised that the interviewer prepare 'warm-up' questions since this has been demonstrated to be an effective way to ease into the interview and build a connection with the participant (Cridland et al., 2016).

Moreover, it is recommended that interview questions be single-faceted and concise to support clarity and limit confusion (Cridland et al., 2016; Quinn, 2017). Leading questions should also be avoided in order "to normalize and encourage open discussion of potentially difficult topics and facilitate non-bias responses" (Cridland et al., 2016, p. 5; Alzheimer's Society, 2020). Providing an introduction and/or disclaimer to perhaps more difficult interview questions and topics was also found to be helpful (e.g., "Some people find the next question difficult…") (Cridland et al., 2016, p. 5). Additionally, a pilot or trial run of the interview guide with persons with dementia is advised before initial data collection to identify areas that may be confusing or unclear and to help the interviewer familiarize themselves with the guide (Alzheimer’s Society, 2020; Cridland et al., 2016). Two selected participants with dementia will participate in a pilot run of the interview to check for the interview questions and process for comprehensibility.

Interviews with Caregiving Spouses

The trained research assistants and I will conduct the interviews with caregiving spouses utilizing an interview guide (Appendix B). As mentioned, interviews will be held in their private bedrooms or at an allocated space in the home to maintain privacy and confidentiality. Caregiving spouses will be contacted prior to enable scheduling around the care homes routines, caregiving duties, and personal appointments. Interviews will last approximately 60 to 90 minutes per participant.

Focus Groups Staff in Care Homes

One focus group session will be conducted per LTC study site with 5-7 care staff in each session. As indicated earlier, the number of LTC sites will depend on the presence of resident spouses with dementia in the two health regions. The project coordinator and research assistants will facilitate the focus group sessions. They will act as moderators and notetakers for participant answers, discussion content, as well as observers of "non-verbal interactions and the impact of the group dynamics" (Nyumba et al., 2018, p. 23). Focus group sessions will be completed at either the LTC home's (one session per site) in consideration of convenience or at a nearby community settings.

The physical setting arrangement of the sessions will include having the participants sit around a table for approximately 45-60 minutes, depending on participant engagement (Liamputtong, 2015; Stewart et al., 2007). Participants will also be given nametags to write only their first names to protect privacy (Stewart et al., 2007). Having participant nametags is hoped to help encourage rapport between participants and the research team and facilitate discussion (e.g., directing questions) and notetaking/observations (Stewart et al., 2007). In addition, each participant will be given $25 as honorarium for their participation. Light refreshments will also be provided during each session. An interview guide for the sessions has been developed and can be found in Appendix D.

The emergent themes from resident interviews will inform the covered topics, therefore the interview guide will be adjusted accordingly. The interview guide consists of six open-ended questions that cover the care practices, policies, staff observations/perspectives about the impacts of separation on persons with dementia, and environmental features of LTC settings that challenge couples' abilities to maintain their relationship. Also, noting the unique circumstances of resident couples and the potential differences between care homes policies and procedures, moderators will encourage participants to share their personal stories regarding their experiences and care practices with resident couples (Stewart et al., 2007). Lastly, each focus group session will be recorded via audio/tape recorder to complement the notetaking and participant observations (Stewart et al., 2007).

4.6. Data Analysis

Data analysis for this study will be comprised of four stages. The first stage will involve the analysis of resident couple interviews of both spouses separately. This analysis will be done to gain insight into the psychological and physical health effects that each individual may face due to separation. The second stage will examine both spouses' interviews simultaneously to understand how separation in LTC impacts the marital relationship and the challenges that the couple faces in maintaining their sense of couplehood. The third phase will evaluate the data collected from the focus group sessions with care staff to address LTC's socio-physical environmental influences on couples' opportunities to maintain their relationship and gain insight into participants' understanding of couples' needs within LTC. Finally, the fourth stage will entail consideration of the three phases, collectively. Within the context of data triangulation, transcripts from resident couple interviews and care staff focus groups will be compared and analyzed for convergent, complementary, and divergent findings (Lambert & Loiselle, 2008).

Braun and Clarke’s (2006) six-step framework of thematic analysis will be utilized to inform the analysis process to identify, describe, organize, and present the themes, i.e., “patterns in the data that are important or interesting” discovered from the data set (Braun & Clarke, 2006; Maguire & Delahunt, 2017, p. 3353). This framework not only permits a data description that is rich in detail but also enables constructive interpretation (Braun & Clarke, 2006; Maguire & Delahunt, 2017). The six stages are as follows: (1) Becoming familiar with the data (2) Generating initial codes (3) Searching for themes (4) Review themes (5) Defining and naming themes (6) and Producing the report (Braun & Clarke, 2006). A detailed description of the application of the framework is explained below.

Six-step Framework of Thematic Analysis

The first step will involve transcribing the audio recordings of each interview and focus group session. The transcription service in NVivo will be utilized. The practice of transcribing not only creates a written record of each interview and group discussion but enables researchers to familiarize themselves with the data, gain a comprehensive understanding of the data, and generate the early stages of analysis by identifying patterns and relationships (Stewart et al., 2007). After transcription, the researcher should read and re-read the data “in an active way – searching for meanings [and] patterns” that will start to inform the subsequent formal coding process (Braun & Clarke, 2006, p. 17). The research team will also participate in memo-writing throughout the analysis process to aid in our understandings and interpretations of the data (Corbin & Strauss, 1990).

The second phase of generating initial codes involves the initial data organization of identifying and constructing codes into meaningful groups (Braun & Clarke, 2006; Maguire & Delahunt, 2017). An inductive coding technique will be adopted, allowing for "research findings to emerge from the frequent, dominant or significant themes inherent in raw data" (Thomas, 2003, p. 2). Thus, coding will be completed in stages, first through initial line-by-line coding, which will enable a descriptive analysis, and then through focused coding in which larger amounts of data will be incorporated and organized (Charmaz, 2014). The statistical software of NVivo (version 12.6.0) will be utilized throughout the coding process. Following the software, the data will be systematically coded into nodes and sub-categorized into sub-nodes to capture topics of significance and repeated patterns (Corbin & Strauss, 1990). Finally, transcripts will be coded separately in relation to the research questions and will be compared, discussed, and modified if needed before moving to the next phase of searching for themes. Within the analysis of interviews with persons living with dementia and focus group sessions, transcripts will be supplemented with observational data taken from video recorded interviews and notes during the focus groups sessions (Stewart et al., 2007). Thus, capturing non-verbal cues (e.g., gestures, facial expressions, and tone) not expressed in the transcripts (Stewart et al., 2007).

In the third stage, the research team will begin to search for themes. Braun and Clark (2006) explain that a theme is characterized as a pattern within the data representing an aspect of significance or interest regarding the research question. This phase is “where the interpretative analysis of the data occurs, and in relation to which arguments about the phenomenon being examined are made” (Braun & Clarke, 2006, p. 18). The codes will be sorted and combined into groups to create overarching themes (Braun & Clarke, 2006). Each group of transcripts, spousal caregiver, the spouse with dementia, and focus group sessions will be first coded for themes separately within this phase. Subsequently, the initial codes from each group will be coded collectively, and the research team will begin to identify convergent, complementary, and divergent findings. Like the initial coding phase, the research team will collaboratively discuss “the relationships between codes, between themes, and between different levels of themes (e.g., main overarching themes and sub-themes within them)” to form what the authors call candidate themes (Braun & Clarke, 2006, p. 20). Knowledge gaps and reasoned conclusions about the themes concerning the research questions will begin to be developed (Farquhar & Michels, 2016).

In the fourth stage, themes will be reviewed and refined (Maguire & Delahunt, 2017). During this stage, the research team will begin to examine and modify the candidate themes to ensure that they "cohere together meaningfully, while [having] clear and identifiable distinctions between [them]" (Braun & Clarke, 2006, p. 20; Maguire & Delahunt, 2017). A thematic map will be created to visually outline the candidate themes' and support the identification of relationships and variants between data sets (Braun & Clarke, 2006; Lambert & Loiselle, 2008). Furthermore, data that may have been missed in the themes or seen as outliers will also be coded at this time (Braun & Clarke, 2006). The fifth stage entails defining and naming themes. During this stage, the research team will continue to examine the data, fine-tune the coding of themes, and further develop each theme's portrayed narrative relevant to the research questions (Braun & Clarke, 2006). During this phase, the thematic map will be further refined to accurately portray the analytic narrative (Braun & Clarke, 2006). According to Braun and Clarke (2006), within this phase, researchers must consider how each theme connects, the possible hierarchy between them, and the sub-themes within them (Braun & Clarke, 2006). Lastly, within this phase, themes and sub-themes names will be finalized used within in the write-up and final analysis (Braun & Clarke, 2006).

Finally, the sixth phase will encompass the final analysis and explanation of the results (Braun & Clarke, 2006). Braun and Clarke (2006) emphasize that the write-up should "tell the complicated story of your data in a way which convinces the reader of the merit and validity of your analysis" (p. 23). Therefore, data extracts such as quotations from interviews and focus group sessions as examples within the analytic narrative will be implemented to aid in the development/presentation of argument and story (Braun & Clarke, 2006). The final report will present a concise synopsis and analysis of the relational aspects between the themes. The thematic map will further be used as a visual aid (Braun & Clarke, 2006).

Chapter 5.

CIHR Grant Proposal

The following section presents a simulated grant proposal based on the CIHR Project Grant: Fall 2020 and Spring 2021 guidelines, as outlined in Appendix K.

5.1. Proposal Information

5.1.1. Project Title

5.1.2. Lay Title

5.1.3. Lay Abstract

The involuntary separation of married couples in long-term care (LTC) settings when spouses require different levels of care has been a common practice in British Columbia (B.C.). While this is a recognized issue, there have been very few studies that specifically examine this topic. In light of this research gap, the purpose of the proposed CIHR grant will be to critically examine the institutional practice of separating married couples in LTC settings in B.C. when one spouse lives with dementia and requires different care and support needs. The proposed empirical study will focus on the abilities and challenges of couples to maintain the desired relationship quality in LTC settings when separated, and how their separation has impacted each spouse's health and well-being. Overall, this project will help guide future research, practice, and policy in this important yet understudied topic in gerontology.

Therefore, the proposed study will address the following two overarching research questions:

- **Research Question 1:** How does the current practice of separating married couples between LTC settings (including AL and IL) when one spouse is living with dementia and resides in LTC impact the marital relationship and couples' abilities to sustain couplehood?
- **Research Question 2:** How does the LTC socio-physical environment influence couples' opportunities to maintain their relationship?

By addressing these research questions, the study will examine couples' abilities and challenges to maintain the quality of their relationship when separated in LTC settings and investigate how separation and perhaps loss of couplehood influence both spouses' health and well-being. Question one investigates the impact of separating married couples on spousal relationship quality, while the second question will provide insight into how the socio-physical environment of LTC may influence couples' capacity to maintain their desired relationship quality. The findings will be highly instrumental in refining existing policies to better support the continuity of spousal relationships in LTC settings. Consequently, we will be able to develop innovative initiatives that will support a couple's emotional needs and improve and/or sustain their overall health and quality of life in LTC settings.

Institution Paid:
Simon Fraser University, Department of Gerontology
Partnered/Integrated Knowledge Translation (iKT) Project:
No.
Containment Level:
No.
Environmental Impact:
N/A.
Is this a clinical trial?
No.
Does this application contain a random control trial?
No.
In order to carry out the proposed research in this application, is an exemption from Health Canada under Section 56 of the Controlled Drugs and Substances Act required?
No.
Does this application propose research involving Indigenous People?
No.
Does your proposal address TCPS2 – Chapter 9 Research Involving the First Nations, Inuit, and Metis Peoples of Canada?
No.

Is sex as a biological variable taken into account in the research design, methods, analysis and interpretation, and/or dissemination of findings?
No.
Is gender as a socio-cultural factor taken into account in the research design, methods, analysis and interpretation, and/or dissemination of findings?
Yes.

This project incorporates sex and gender into the research design, methodology, and analysis when defining marriage and marital relationships. Married couples are defined within the Family Law Act of B.C which defines a spouse as "is married to another person or has lived with another person in a marriage-like relationship and has done so for a continuous period of a least 2 years" (Family Law Act, 2011). Within this act, both common-law relationships and non-heterosexual relationships (LGBTQ+) are recognized. Thus, spousal relationships are identified as an ongoing relationship between two individuals in which partners share emotional, financial, and social attachment for an extended period, rather than solely depending on the legal definition of relationships (Føsund, 2017; Hunt, 2015; Braithwaite, 2002; Walker & Luszcz, 2009). The above consideration will be applied within the recruitment of couples, how data is interpreted and analyzed, and how findings are disseminated. For example, considering traditional gender roles in marriage (e.g., caregiving and homemaking), noting that there are typically more women than men in LTC settings and that there are traditionally more women caregivers than men. Thus, findings and policy recommendations need to take into account these gender differences.

Furthermore, although not the primary focus, this study will consider the perceptions and experiences of those who identify as LGBTQ+—understanding the additional barriers and stigma faced by couples who identify as LGBTQ+ and how it impacts the preservation of their relationship within the institutional environment of LTC settings. For example, LGBTQ+ older adults' fears concerning inadequate care, staff neglect, lack of recognition of their relationship, and discrimination and harassment from other residents or staff members (Malone, 2016).

5.2. Subtask: Descriptors

Descriptors

Long-term care; Older couples; Separation; Marital relationship; Couplehood; Physical health; Emotional well-being; Dementia

Themes

1. *Health Services Research* is the primary theme classification for this grant application. This research fills the existing knowledge gap surrounding married couples' experiences within LTC settings to improve health professionals' efficiency and effectiveness and the health care system for this growing population. It further aims to extend and complement prior research involving persons with dementia perspectives and the subjective experiences of dyadic relationship well-being. The funded research will be highly instrumental in refining existing policies and practices to develop innovative initiatives/interventions that will support a couple's emotional needs and improve and/or sustain their overall health and quality of life in LTC settings.
2. *Social, Cultural, Environmental and Population Health Research* is a complementary theme of this grant application. An important research goal is to better understand the situations and lives of Canadas ageing couples who are involuntarily separated in LTC settings as a result of one spouse’s different needs of care. In effect, to develop supportive interventions and policies that will improve their health and quality of life within LTC settings.

Suggested Institutes

The Department of Gerontology at Simon Fraser University (SFU) has a related research mandate to the CIHR Institute. The Gerontology Research Centre (GRC), which works collaboratively with the department, acts as a centrepiece for information, research and education concerning individual and population ageing in many areas connected with the proposed research.

Areas of Science

- Aging- Social Determinates of Aging
- Health Services and Systems- Access to care; Healthcare Effectiveness & Outcomes; Knowledge Translation Research and Implementation Science; Personalized Medicine
- Population Health- Population Health Intervention Research; Health Equity

Methods/Approaches

Qualitative Methods: Interviews & Focus Groups

Patient Oriented Research: Patient-Centred Care

Lived Experience: Lived Experience

Population & Social Science Methods: Family Studies & Health Services Research

Knowledge Translation: Translation Research

Evaluation & Intervention Research Methods: Policy Analysis & Evidence-Based Practice Approaches

Study Populations/Experimental Systems

Primary Study Population:

- Life Stages: Older adults

Secondary Populations:

- Patients and Caregivers: Informal Caregivers & People with diseases or conditions
- Social, economic, and legal status: Family Relationships

5.3. Research Proposal

5.3.1. Concept

Significance and Impact of Research

Canada's changing demographics due to increased longevity and population ageing means that more married couples than ever before will live to share the experience of old age (Kemp, 2008; Milan et al., 2014). In light of these increasing life expectancies, it is estimated that more older couples will experience a caregiving relationship in which one spouse faces health declines such as dementia (Hellström et al., 2005; Milan et al., 2014). Recent estimates show that 46% of caregivers to a person with dementia are spouses and that 99% of them live in the same household, with 97% providing daily care (Wong et al., 2016). The experience of couples when one spouse has dementia is often portrayed in the literature as a life of loss, frustration, burden, and stress, with spousal caregivers experiencing a multitude of adverse health consequences (e.g., depression and anxiety) (Swall et al., 2019). However, being a spouse and caregiving for a person with dementia "is not a uniformly negative experience," with many caregiving spouses expressing positivity and satisfaction in their role (Førsund et al., 2015, p. 122). The marital relationship of older couples is unique as decades of shared experiences and closeness result in a shared sense of identity, creating a powerful partnership that is resilient to challenges (Hernandez et al., 2019). Understanding the uniqueness of the marital relationship of older adults, many spouses can maintain their desired relationship quality, which connects to the emergent concept of couplehood in dementia research, defined as "the relationship between two committed individuals, characterized by a sense of…shared identity, a sense of purpose, and commitment" (McGovern, 2012, p. 5). Nevertheless, the progressive nature of dementia can often lead to increasingly intense caregiving responsibilities, which can be taxing on ageing spousal caregivers who may be facing health challenges of their own (Kemp, 2008; Wong et al., 2016). These circumstances can challenge a couple's ability to live independently in their homes, driving their collective relocation into a long-term care (LTC) setting (Kemp, 2008; Wong et al., 2016).

Research reveals that while the decision to relocate may be primarily driven by the needs of one spouse, both spouses were united in the decision, as a result of their strong aspirations and marital commitments to remain together (Kemp, 2008, 2012). As of 2016, it has been reported that 9.2% of women and 4.9% of men aged 65 years and older live with a spouse in a primary health care and related facilities, such as LTC settings (Statistics Canada, 2017; Wister, 2019). These numbers jump to 35.6% of women and 23.1% of men when aged 85+ (Statistics Canada, 2017; Wister, 2019). Although the number of older couples who reside in LTC settings is a small percentage, with the ageing baby boomer population, it is predicted that couples relocating together will increase as longevity increases (Gladstone, 1992; Milan et al., 2014). However, institutional practices in British Columbia (B.C.) Canada invokes the separation of married couples in LTC settings, such as having one spouse reside in assisted living (AL) or independent living (IL), and the other with more complex care needs reside in LTC. This practice, although sparse in academic research has received significant media attention in recent years. For example, a report in The Globe and Mail (2016) emphasized how the involuntary separation of a couple in which one spouse had dementia impacted each spouse's emotional and physical health status. The article stated that their separation into two different LTC settings fueled symptoms of depression and anxiety and provoked the rapid decline in cognitive status of the spouse with dementia (Kane, 2016). The strong aspirations exhibited by couples' to remain together emphasize the importance of their desire to continue their relationship when in LTC (Kemp et al., 2016). Studies have found that the ability to maintain a sense of couplehood an essential aspect in the lives of couples where one spouse has dementia (Førsund & Ytrehus, 2018). Despite this, no empirical research to date has addressed the impacts of forced separation of couples in LTC settings and the experiences of both spouses, including those with dementia.

The B.C. Ministry of Health has recognized the significance of relationships among older couples within LTC settings, developing a provincial policy that aims to ensure the "continuity of spousal relationships when only one spouse requires [LTC] services" (British Columbia Ministry of Health, 2019, sect. 6.D.1, p.1). The policy obliges homes to establish reasonable arrangements for spouses to live in the same home to maintain contact and relationship (British Columbia Ministry of Health, 2019). However, as the policy details are fairly recent, the conditions in terms of how close in proximity spouses will reside are vague, and the implications have not yet been evaluated. Furthermore, there are significant barriers to the execution of the policy as a result of the current COVID-19 pandemic, beginning in March of 2020. Therefore, it is unclear if LTC homes have even exercised this policy or if the pandemic has impacted the policy's future utilization. Considering this lack of transparency and in light of the novelty of the policy, the proposed study will aim to address our knowledge gaps in this area.

Research to better understand the experiences and lives of older couples in LTC is essential. Many older couples desire to remain together for as long as possible despite declining health (Harrefors et al., 2009; Kemp, 2008). The involuntary separation of couples and their determined loss of couplehood is demonstrated in research to have determinantal health consequences (e.g., Hemingway et al., 2016; Glasier & Arbeau

2019). The lack of research concerning the impacts of separation on both spouses, including persons with dementia, disregards couples shared experiences and critical elements of each spouse's identity. The health and well-being of married couples must be looked at as a unit instead of separate beings (Mullin et al., 2013). The importance of their relationship within their quality of life should be a central concept in creating policy initiatives for couples in LTC settings (Mullin et al., 2013). This work will examine the lived experiences of couples in LTC settings when both reside in care, a topic that is currently underrepresented in gerontological research.

Purpose

The purpose of this study is to critically examine the institutional practice of separating married couples in LTC settings in B.C. when one spouse lives with dementia and requires different care and support. In particular, the proposed empirical study aims to extend and complement prior research involving persons with dementia perspectives and the subjective experiences of dyadic relationship well-being. Although there is ample literature exploring the impacts of LTC's socio-physical environment on visiting spouses (still community-dwelling) abilities to maintain their sense of couplehood, the examination of couples' challenges when both spouses reside in an LTC setting is meagre.

The completed scoping review guiding the proposed study uncovered a number of knowledge gaps establishing the need for further inquiry into the lived experiences of married couples residing in LTC, a population currently underrepresented. In specific, there is a current lack of research that addresses the perceptions of both spouses (i.e., the caregiving spouse and the spouse with dementia), thus, disregarding both spouse's experiences. This is imperative when focusing on research that is exploring the relationships of couples itself. In effect, there is a clear gap in research concerning a couple's sense of unity within their everyday lives and how that transposes into providing care and the marital relationship when one spouse has dementia (Swall et al., 2019). This omission presents a significant gap in knowledge, as it neglects a core characteristic of person-centred/person-directed care practices of maintaining familial bonds and including family in care (Alzheimer’s Society of British Columbia, 2011). In addition, there is a lack of literature that addresses how the LTC's socio-physical environment, such as attitudes of care home staff and the environmental features (e.g., meal seating arrangements, the distance between units, etc.) influence couples' opportunities and abilities to meaningfully interact with each other.

As articulated in the research questions below, the proposed empirical study will examine couples' abilities and challenges to maintain the quality of their relationship when separated by the policies and practices of LTC settings and investigate how separation and perhaps loss of couplehood influence both spouses' overall health and well-being. The proposed study will contribute to the limited empirical research concerning this specific population. This research will be valuable in that it will critically evaluate the procedures and culture of care that impact a couple's abilities to maintain their relationship. In particular, the funded research will be highly instrumental in the refinement of existing policies to better support the continuity of spousal relationships in LTC settings. Consequently, we will be able to develop innovative initiatives that will support a couple's emotional needs and improve and/or sustain their overall health and quality of life in LTC settings.

The study will be guided by two overarching research questions with five sub-questions:

- **Research Question 1:** How does the current practice of separating married couples between LTC settings (including AL and IL) when one spouse is living with dementia and resides in LTC impact the marital relationship and couples’ abilities to sustain couplehood?
    - **Sub-Question:** What are the challenges couples face in maintaining couplehood?
    - **Sub-Question:** What are the mental and physical health effects both individuals may face when separated in LTC settings? (e.g., responsive behaviors in persons with dementia, depression, anxiety, malnutrition).
- **Research Question 2:** How does the LTC socio-physical environment influence couples’ opportunities to maintain their relationship?
    - **Sub-Question:** What is the understanding of care home staff (e.g., nurses, care-aids, directors of care, and executives) of couples’ needs in LTC?

- **Sub-Question:** What policies and care practices act as barriers in couples' capacity to maintain the desired aspects of their relationship in the LTC environment?
- **Sub-Question:** What physical environmental features of the LTC setting inhibit couples' capacities to interact meaningfully? (e.g., locked units, locks on private bedroom doors, distance between units, lack of privacy).

5.3.2. Assessment of Feasibility

Approaches and Methods

Design

To address the proposed research questions, the study will adopt a qualitative research method design with two components, interviews with resident couples and focus groups with LTC care staff. Applying a data triangulation approach that involves utilizing two methods of qualitative inquiry is beneficial for increasing validity, attaining more comprehensive data, and gaining a better understanding of the phenomenon under investigation (Lambert & Loiselle, 2008; Perlesz & Lindsay, 2003). The methodology of combining the perspectives of resident couple interviews with care staff focus groups will afford a deeper and more comprehensive investigation of the subjective experiences of older couples and the culture of care in LTC settings that challenge couples' abilities to maintain their desired relationship quality. Within this project, the two methods are used to form an iterative technique in which focus groups are utilized as a subsequent phase after completing resident couple interviews. The emergent themes from interviews will therefore inform the topics and questions addressed in the focus groups with care staff.

In the first phase, face-to-face semi-structured interviews with 10-12 couples at multiple LTC or Assisted/Independent Living facilities (AL/IL) (one spouse lives in LTC and the other living in AL/IL) in Metro Vancouver, B.C. will be conducted. In recognition of the gap in knowledge surrounding the impacts and subjective experiences of involuntary spousal separation on persons living with dementia, interviews will be completed with both spouses, including those with dementia. This will result in a total number of 20-24 interviews. These interviews will be used to gain insight into older couples' lived experiences separated in LTC settings and how their separation and potential loss of couplehood has impacted each spouses' health and well-being.

The inclusion of persons with dementia’s perspectives and experiences is critical in this study. It is imperative for understanding how separation from a spouse within LTC settings impacts their health, well-being, and overall quality of life. The collaborative and flexible nature of semi-structured interviews has been demonstrated in research as an appropriate and valuable method to gain insight into persons with dementia's perspectives and experiences (Cridland et al., 2016; Mazaheri et al., 2013). For example, semi-structured interviews enable the development and use of an interview guide with specific questions/topics to be covered; however, the interviewer can diverge from the guide when deemed appropriate to follow the topical trajectories of the interview (Hesse-Biber & Leavy, 2006). This interview structure allows for a more genuine conversation, offering participants the opportunity to digress into topics and ideas that the researcher may not have anticipated (Hesse-Biber & Leavy, 2006). This flexibility further allows the interviewer to respond and inquire about emergent topics of importance (Hesse-Biber & Leavy, 2006).

The second phase involves conducting focus groups with LTC home care staff. Specifically, these focus groups will comprise of nurses and personal support workers from the participating Metro Vancouver LTC homes in which the spouse with dementia resides. Each focus group will consist of 5-7 care staff, with one session conducted per participating site. Questions will be open-ended with the intent to promote discussion (Nagle & Williams, 2020). Supplementing the resident interview data with information gained from LTC home staff focus groups will achieve a deeper understanding of LTC settings' socio-physio environmental features (e.g., layout, the culture of care/intuitional protocols and practices, and staff understanding) that challenge couples' abilities to maintain their relationship.

This study will involve multiple LTC homes and AL/IL facilities in Metro Vancouver, B.C., located in the Vancouver Coastal Health (VCH) and Fraser Health Authorities (FHA). The LTC homes and AL/IL facilities will be selected based on availability of access for the researcher team and presence of married couples who fit the inclusion criteria. This identification process will be conducted in close consultation with leadership team in LTCs/ALs/ILs at VCH and FHA. The inclusion of different LTC homes and AL/IL facilities will also allow to explore potential variations in organizational culture, policy, and practice. Focus groups with LTC staff will be completed at the LTC homes or at convenient community settings. Appendix H provides a detailed 3-year project timeline to complete this project.

Sampling and Recruitment

Both resident couples and care staff participants of the selected homes will be recruited with the support of identified LTC homes' executive directors and AL/IL administration. The leadership members at selected sites will be contacted via email or telephone to determine if couples in their homes fit the study's interest and inclusion criteria, which will be explained below. Once executive directors/administrators have consented to their LTC/AL/IL to partake in the study, they will identify care home staff that will help select resident couples who fit the inclusion criteria and would be interested in participating. The identified care staff will also act as a liaison between myself, research assistants and the couples. Research assistants will conduct this study with interviews and focus groups completed in person. This study is highly feasible since the primary gatekeepers (i.e., the executive board) and the participants will perceive strong benefit from this research, thus presumably will consent to the study, as consistent with other types of studies of this kind (e.g., Førsund & Ytrehus, 2018; Hunt, 2015).

Resident Couples

The 10-12 couples participating in this study will be recruited using the purposeful sampling technique of criterion sampling (Patton, 2015). Inclusion criteria for the spousal caregiver include (i) having each participant fluent in English, (ii) partner in a long-standing committed and/or marital relationship, (iii) residing in an LTC home or AL/IL facility, (iv) having a spouse with dementia living in a care home, and (v) being involuntarily separated from their spouse because of their spouses care needs. Inclusion criteria for persons with dementia include (i) English speaking, (ii) having a previous diagnosis of some type of dementia (e.g., Alzheimer's disease or vascular dementia), (iii) having enough language and communication ability to participate (e.g., having a cognitive performance scale number as being 1 = borderline intact (MMSE score of 22) to 2 = mild impairment (MMSE score of 19), or potentially 3= moderate impairment (MMSE score of 15), however, interview questions would need to be further adjusted), (iv) the ability to give consent, and (v) voluntarily wanting to participate and share their experiences. The selection of persons with dementia and determination of eligibility will be completed with the input of care staff. The determination of persons with dementia participants' capacity to provide consent is explained in detail below.

Furthermore, eligible participants will be selected not only from the inclusion criteria stated above, but with consideration to participant interest and couples' circumstances (e.g., life history/story and situation within the LTC home or AL/IL). The definition of marriage in this study aligns with the Family Law Act of B.C., which includes both common-law relationships and non-heterosexual relationships (LGBTQ+) (Family Law Act 2011). Thus, participants' spousal relationships included in this study will not solely be based on legal recognition, but couples committed and shared emotional attachments and experiences (Braithwaite, 2002; Walker & Luszcz, 2009). A potential challenge identified will be the location and recruitment of a population that is a minority in LTC settings. The research team will work collaboratively with care homes, executive directors, and care staff, to identify as many resident couples as possible who fit the inclusion criteria in Metro Vancouver.

Care Staff Focus Groups

Focus group participants will include nurses and direct care staff (personal support workers) from LTC homes in which the spouse with dementia resides. Each focus group will consist of 5-7 care staff, with one session conducted per participating site. LTC home care staff were selected to gain perspective into the organizational culture and socio-physical environment of LTC that can impact couples' abilities to meaningfully interact. LTC home care staff furthermore will provide a complementary perspective into the impacts of separation on persons with dementia, such as perhaps changes in their mood/behaviours when alone or with their spouse. LTC home care staff will be recruited through purposeful sampling and include care staff who are who are often in contact with the identified married residents (Palinkas et al., 2015). The recruitment poster is shown in Appendix J will also be placed within the homes. Focus group inclusion criteria will involve having each staff member be English speaking, be either a nurse (i.e., registered nurse (RN) or licensed practical nurse (LPN)) or personal support worker working within the LTC setting of the spouse with dementia.

Ethical Considerations and Informed Consent

Both spouses and all focus group participants will be required to sign a written consent form (Appendices E, F & G). The consent form will describe the study's purpose, their participation, and detail participant confidentiality. The form will also explain the participant's abilities to withdraw from the study at any point in time. There are important ethical considerations and challenges when including persons with dementia in research. A principal concern is the participants' ability to provide informed consent (Howe, 2012). Informed consent is described as an autonomous decision by a person deemed competent to sanction their research participation (Lepore et al., 2017). Persons with dementia participants' capacity to consent "depends on whether he or she can communicate relatively consistently, understand basic information about choices, evaluate the implications of different choices, and rationally comprehend the risks and benefits associated with different options" (Lepore et al., 2017, p. 3). The principles of the process consent method will be applied (Dewing, 2007, 2008). There are five aspects of process consent which views consent as an ongoing process, practices assent, and respects the decisions of dissent from participants: (1) Background and preparation (2) Establishing a basis for capacity and other abilities (3) Initial consent (4) Ongoing consent monitoring (5) Feedback and support (Dewing, 2008). First, permission will first be gained from the care staff and the participant's spouse to access the person and gain biographical information (Dewing, 2007). Members of the research team will visit participants before gaining consent to form a trusting relationship with participants and observe/understand participants' personalities (Dewing, 2007). Gaining descriptions of non-verbal cues such as facial expressions and overall demeanour can aid in the ability to evaluate ongoing consent (Dewing, 2007, 2008).

Secondly, establishing a basis for capacity and other abilities involves the researcher's own assessments in the decision-making process of the eligibility of participants (Dewing, 2008). The researchers utilize their knowledge and understanding of participants in consideration to a "significantly less emphasis on the person's ability to retain information and appreciate consequences and more on how it feels to the person in broad terms" (Dewing, 2008, p. 62). Thus, participants' consent will be continuously evaluated and examined by the research team, who will note any decisive behaviour that may demonstrate the persons' desire to dissent (Dewing, 2008). Thirdly, initial consent, as described by Dewing (2007, 2008), moves away from traditional conceptualizations of consent and involves providing information to participants in a manner that respects their "abilities and preferred ways of receiving information" (Dewing, 2008, p. 63). Initial consent will be gained through both verbal consent and adapted written consent forms (Dewing, 2007). In addition, in cases where the person is deemed unable to provide informed consent, their spouse (or if another person is legally recognized such as an adult child) will act as their substitute decision maker and will provide consent and sign their consent form on their behalf (Dewing, 2008; Lepore et al., 2017) Within the consent form, participants will be given the option to permit researchers to video record interviews. Audio recordings will further be offered as an alternative option. Detailed notes will be taken during the interviews concerning the participant's body language and non-verbal cues to understand how consent/assent are given in the person with dementia's everyday life (Dewing, 2007). Additionally, ongoing consent monitoring involves the continuous assessment of consent throughout the interview process (Dewing, 2007, 2008). Participants will be reminded about the purpose of the research as well as their rights to withdraw from the study if they wish, and thus monitor for any signs of verbal and non-verbal signs of dissent (Dewing, 2007, 2008).

Lastly, the fifth element of feedback and support encourages key stakeholders' involvement and feedback if issues or concerns arise in the field and during the interview process (Dewing, 2007, 2008). The research assistants will notify the project coordinator if a concern arises, who will then gain the feedback and necessary involvement of care staff, or the participant's spouse to help resolve the issue (Dewing, 2007, 2008). Additionally, spouses and care staff will be given contact information (phone number or email address) to inform the research team if there are any changes in the person with dementia as a result of the research before resuming the interview process (Dewing, 2007). Dewing (2007) notes that researchers should consider the person with dementia's abilities to transition back into their daily routines from the research context. The aid of care staff members will be enlisted when the interview sessions are complete to help the person with dementia transition back into their daily routines and note the interventions needed. Finally, in situations where it becomes necessary to express to care staff specific concerns from the participant, the project coordinator will first ask permission from the person with dementia to bring forth their concerns and do so while respecting confidentiality (Dewing, 2007).

Data Collection

Research assistants will conduct semi-structured interviews with resident couples and care staff focus groups. To uphold confidentiality, interviews with resident couples will be completed in either a participant's private bedroom or at an allocated private space within the facility that can be utilized with permission (e.g., conference rooms, family visiting rooms, etc.) Interview times with resident couples will be coordinated around the care home's routines (e.g., meals and activities), caregiving duties, and personal appointments. Interviews will last approximately 60 to 90 minutes per participant. Interview guides for both spousal caregivers and persons with dementia have been developed and can be found in Appendices B and C. The interview guides are based on the study's research questions and build upon a completed scoping review that identified themes and relevant research gaps. In addition to notes taken during the interviews, interviews with both spouses will be recorded via tape recorder. Having audio recordings of each interview is imperative since it ensures that interviewees' responses are accurately represented and that comprehensive data is collected (Charmaz, 2006; Patton, 2015).

Conversational Interviews with Residents with Dementia

There are several pragmatic elements to consider when conducting interviews with persons with dementia (Cridland et al., 2016; Quinn, 2017). Firstly, interviews need to be conducted in an environment with minimal distractions, which can be difficult in a care home setting (Quinn, 2017). A person’s place of residence has often been chosen to interview persons with dementia as they “prom[ote] familiarity for participants; ga[in] insight into the life of people with dementia; and having environmental cues which may facilitate the interview” (Cridland et al., 2016, p. 11). In consideration of this study’s inquiry into the sustainment of couplehood within the boundaries of the LTC environment, completing the interview in the person’s private bedroom can not only provide the quiet/private place to complete the interview but further aid in the promotion of recall, reminiscence or the identification of important issues (Cridland et al., 2016, p. 11). However, interviews would also be completed in a designated area in the home (e.g., conference rooms or family visitation rooms) if the person feels more comfortable. Secondly, interviews will be scheduled "at an appropriate time of day for participants (e.g., avoiding late afternoon interviews when participants may be tired and/or considering the impact of medication)" and must factor in the person's feelings day by day (Cridland et al., 2016, p. 11; Quinn, 2017). Thus, care staff will be contacted before completing the interview to find the best time and assess how participants may feel and if they would be interested in participating that day (Cridland et al., 2016; Quinn, 2017). Additionally, A pilot or trial run of the interview guide with persons with dementia is advised before initial data collection to identify areas that may be confusing or unclear and to help the interviewer familiarize themselves with the guide (Alzheimer's Society, 2020; Cridland et al., 2016). Two selected participants with dementia will participate in a pilot run of the interview to check for the interview questions and process comprehensibility. Lastly, it is suggested that interviewers understand the progression of dementia and know of supportive communication strategies (Cridland et al., 2016). For example, interviewers must allow space for larger amounts of time, must be able to rephrase questions if the person looks confused, and must be aware of participants' body language throughout the interview to note when the person may need to take a break and practice ongoing consent (Harman & Clare, 2006; Quinn, 2017). Therefore, research assistants must have the appropriate personality characteristics and be required to refer to journal articles and other resources before interviewing to ensure sensitivity to interview pace and characteristics of dementia (Brinkmann, 2007).

Focus Groups Staff in Care Homes

One focus group session will be conducted per LTC study site, with 5-6 care staff in each session. As indicated earlier, the number of LTC sites will depend on the presence of resident spouses with dementia in the two health regions. The project coordinator and research assistants will facilitate the focus group sessions. They will act as moderators and notetakers for participant answers, discussion content, as well as observers of "non-verbal interactions and the impact of the group dynamics" (Nyumba et al., 2018, p. 23). Focus group sessions will be completed at either the LTC home's (one session per site) in consideration of convenience or at a nearby community settings. The physical setting arrangement of the sessions will include having the participants sit around a table for approximately 45-60 minutes, depending on participant engagement (Liamputtong, 2015). Participants will also be given name tags to write only their first names to protect privacy (Stewart et al., 2007). Having participant nametags is hoped to help encourage rapport between participants and the research team and aid in facilitating discussion (e.g., directing questions) and notetaking/observations (Stewart et al., 2007). Each participant will be given $25 as an honorarium for their participation.

Light refreshments will also be provided during each session. An interview guide for the sessions have been developed and can be found in Appendix D.

The emergent themes from resident interviews will inform the covered topics, and therefore the interview guide will be adjusted accordingly. The interview guide consists of six open-ended questions that will cover the care practices, policies, staff perspectives about the impacts of separation on persons with dementia, and environmental features of LTC settings that challenge couples' abilities to maintain their relationship. Also, noting the unique circumstances of resident couples and the potential differences between care homes policies and procedures, moderators will encourage participants to share their personal stories regarding their experiences and care practices with resident couples (Stewart et al., 2007). Lastly, each focus group session will be recorded via audio/tape recorder to complement the notetaking and participant observations (Stewart et al., 2007).

Data Analysis

Data analysis for this study will be comprised of four stages. The first stage will involve the analysis of resident couple interviews of both spouses separately. This analysis will gain insight into each individual's mental and physical health effects due to separation. The second stage will examine both spouses' interviews simultaneously to understand how separation in LTC impacts the marital relationship and the challenges that the couple faces in maintaining their sense of couplehood. The third stage will evaluate the data collected from the focus group sessions with care staff to address LTC's socio-physical environmental influences on couples' opportunities to maintain their relationship and gain insight into participants' understanding of couples' needs within LTC. Finally, the fourth stage will entail considering the first three stages to gain a comprehensive understanding of the effects of separation on both spouses. Within the context of data triangulation, transcripts from resident couple interviews and care staff focus groups will be compared and analyzed for convergent, complementary, and divergent findings (Lambert & Loiselle, 2008).

Interviews will be transcribed, coded, and analyzed using Nvivo statistical software (version 12.6.0) and the Nvivo transcription service. Braun and Clarke's (2006) six-step thematic analysis framework will be utilized to inform the analysis process (Braun & Clarke, 2006). The six stages are as follows: (1) Becoming familiar with the data (2) Generating initial codes (3) Searching for themes (4) Review themes (5) Defining and naming themes (6) and Producing the report (Braun & Clarke, 2006). The use of this framework enables an in-depth comparison of data across interview and focus group participants (Braun & Clarke, 2006). The research team will code transcripts separately in relation to the research questions and compare, discuss, and modify these initial codes if needed before moving to the next phase of searching for themes. Within the analysis of interviews with persons living with dementia and focus group sessions, transcripts will be supplemented with observational data taken from video recorded interviews and notes during the focus groups sessions (Stewart et al., 2007). Thus, capturing non-verbal cues (e.g., gestures, facial expressions, and tone) not expressed in the transcripts (Stewart et al., 2007). Notably, throughout each stage, the research team will participate in memo-writing to practice reflexivity, enhance understanding and interpretations, promote discussion, and demonstrate transparency and rigour (Corbin & Strauss, 1990).

Knowledge Translation

The CIHR defines knowledge translation (KT) as “a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system” (Canadian Insitute of Health Research (CIHR), 2016, para. 4). The proposed study will adopt the CIHR end-of-grant knowledge translation (KT) approach, which involves creating and implementing a plan to disseminate research findings to knowledge users based on the completed project (CIHR, 2016). This research will help to improve current policies and establish supportive interventions and care practices that promote the continuity of spousal relationships in long-term care settings. Education and collaboration with care staff within LTC settings, health authorities, academics and researchers, and with resident couples and their families will ensure that findings are effectively distributed and integrated into practice.

Knowledge translation of study findings will be threefold. First, this project's primary goal is to increase awareness amongst professionals working within the LTC sector about the lived experiences of couples involuntarily separated in LTC settings and its impacts on their health and quality of life (e.g., nurses, personal support workers, executive directors, directors of care, health authorities, advocates, and policymakers). Specifically, increasing professionals' understanding of couples' unique experiences and situations in LTC settings and be better prepared to empathize and provide support through individualized approaches and care plans that serve each spouse independently and couples as a unit (e.g., that keep couples together, facilitate interactions, and enable the continuation of shared routines, such as having meals together and residing in the same room). With this intention, presentations of findings will be delivered to the LTC homes and AL facilities whose residents and care staff participated in the study. Ideally, these participating homes will utilize the presented findings and translate them into interventions and practices, leading to future partnerships in research and pilot projects. Additionally, presentations and the distribution of plain language summary reports will include organizations and initiatives in Metro Vancouver and B.C., such as the Interdisciplinary Long Term Care Team at VCH, BC Care Providers, and the Alzheimer's Society of B.C. which can aid in the dissemination of knowledge and act as partners in advocacy and education.

Secondly, workshops that present key findings and are engaging to care staff in LTC settings, mainly nurses (RN's and LPN's), personal support workers, executive directors, and directors of care, can be offered in partnership with the organizations mentioned above and their existing person-centred care practice initiatives/education. Partnering with these organizations will enable access to the largest number of LTC settings and care staff in Metro Vancouver, bring a better understanding of care staff schedules/time, and abilities to arrange for these workshops to include pay for attendees (e.g., having attendees have 1-day paid for attending). The workshops will include the presentation and discussion of findings and how they can be applied in care practices and on-going conversations, the development of supportive initiatives, and policy. Workshop participants will be given plain-language summary information packages in which they can use to inform their individual practice.

Finally, research findings will be published in academic journals and reports in order to disseminate results and facilitate knowledge translation among researchers, academics, health care professionals and other key stakeholders. Additionally, members of the research team will present findings at annual gerontology, nursing, and other relevant conferences such as the Canadian Association of Gerontology Conference (CAG), the Nursing and Healthcare Conference, the Canadian Gerontological Nursing

Association annual conference (CGNA), and the annual BC Care Providers Conference. A project budget, found in Appendix I. explains the expenses of this project in detail and how funding will be allocated for knowledge translation.

Expertise, Experience, and Resources

This section will not be included as part of the Capstone project requirements but will be completed in an authentic CIHR grant proposal.

5.4. Summary of Progress

To summarize, my preliminary research and scoping review revealed the following themes: Impact of Physical Separation on Relationship and Health/Well-being, Significance and Meaning of Visiting, Social Atmosphere and Relationships, and Physical Environment. Key findings emphasize the importance of older couples' desires to continue their relationship in LTC, validating previous research demonstrating the importance of couples' abilities to maintain their sense of couplehood as an essential aspect of couples' health and quality of life when one spouse has dementia (e.g., Førsund & Ytrehus, 2018: Hemingway et al., 2016; Hennings et al., 2013). The discovered themes revealed the complex and overwhelming emotional experience connected with involuntary separation and perceptiveness into the culture of care that impacts couples' abilities to sustain their relationship post-relocation.

It was found that spousal carers' health was negatively impacted by their separation, which is intensified by their spouses' progressive deterioration of cognitive abilities (e.g., depression, grief, stress, and anxiety) (Hemingway et al., 2016; Mullin et al., 2013). Comparatively, one study noted that persons living with dementia experience a significant loss of identity as the disease progresses and the changes in their relationship with their spouse (Miskovski, 2017). It was revealed that the dynamics of their relationship change when their spouse transitions into a caregiving role; for example, persons with dementia can feel like a burden to their spouse and expressed that their spouse will talk down to them. Regularly visiting, in turn, provided opportunities to check on their partners' care and advocate for changes, sometimes creating challenging relationships with care staff (Sandberg et al., 2001; Miller, 2019; Braithwaite, 2002). The physical environment was further illustrated to impact spousal caregivers' opportunities to interact with their partners. Issues such as lack of privacy, institutional design/practices such as roommates and care staff interruptions were found to challenge couples' abilities to create a place of meaning and interact (Førsund & Ytrehus, 2018; Heliker & Scholler-Jaquish, 2006). The identified obstacles faced by visiting spousal caregivers in maintaining their sense of couplehood and the implications of involuntary separation provide a valuable glimpse into the unique experiences of married couples in LTC settings.

The results of the review highlight several important research directions. First, the literature failed to address the current issue of involuntary separation of married couples in LTC when one spouse has dementia and requires more complex care, and how this affects couples' ability to maintain their relationship. Second, many studies focused exclusively on the perspectives of spousal caregivers rather than exploring the experiences of both (i.e., the caregiving spouse and the spouse with dementia). Omitting people living with dementia negates the perspectives and opinions of a significant percentage of the population in LTC and the relevance and value of spousal relationships in the lives of many persons living with dementia. Given that little is known about the experiences of both spouses', inquiry into the lived experiences and perceptions of persons with dementia will further help to develop our conceptual understanding of couplehood in LTC settings and provide valuable insight into the impacts of separation and loss of relationship quality on a couple as a unit. Third, the literature demonstrated that care staff often do not understand the role of spousal relationships and couplehood. There is a paucity of literature that showcases the viewpoints of care staff in terms of their understandings of the significance of couplehood and the potential barriers they may face (e.g., policy, education, time constraints) in their abilities to provide space for the continuity of spousal relationships within the LTC environment. Additionally, there is a scarcity of research that examines how the physical design and structure of LTC settings inhibit couples' opportunities to interact meaningfully.

Building upon the scoping review, the proposed study aims to address the current gaps in research by examining the institutional practice in B.C. of separating married couples in LTC settings when one spouse lives with dementia and requires different care and support. In specific, a) couples' abilities and challenges to maintain the quality of their relationship when separated by the policies and practices of LTC, and b) how separation and potential loss of couplehood influence both spouses' overall health and well-being. The study will also explore how the LTC's socio-physical environment, such as staff attitudes and environmental features, affects couples' opportunities and abilities to meaningfully interact with one another. Accordingly, interviews will be conducted with both spouses, including those with dementia. Conducting interviews with both spouses is deemed an appropriate and valuable method to comprehensively understand the phenomena of couplehood in the LTC settings and the challenges couples may face in preserving their desired relationship quality post-relocation. Moreover, investigating the experiences of persons with dementia will provide useful information for improving person-centred practices and education. In addition, interview data will be supplemented with the perspectives of LTC home care staff through focus groups. Focus groups with care staff will provide a more holistic understanding of LTC settings' socio-physical environment and the culture of care that impacts older couples' abilities to maintain desired aspects of their relationship post-relocation. Furthermore, offering vital insight into how or if LTC settings have been transformed (e.g., care practices and physical design) to accommodate married couples under B.C.'s new policy guideline.

Lastly, the current COVID-19 pandemic presents significant challenges in completing field research in LTC homes. If the proposed study is completed during the pandemic, COVID-19 policies and protocols will be withheld in consideration of the safety and health of the residents, care staff, and the research team. The research team will not physically travel to and between different LTC settings to minimize the risk of exposer and spread. Resident couple interviews will be held over the phone or in the form of an available video calling service (e.g., Skype or Facetime). Interviews will further be held within their respective rooms to ensure privacy and warrant social distancing. Care staff focus groups will be held over zoom at their convince. This project will be completed over the course of three years. A detailed project timeline can be found in Appendix H. Three years is deemed a sufficient amount of time to contact LTC homes, recruit residents couples and care staff, gather and analyze data, develop a write up, and disseminate findings. A detailed outline of budget can be found in Appendix I. The budget demonstrates allocated funding to the research team (one project coordinator and two research assistants), travel for data collection (e.g., gas or bus pass), and knowledge translation initiatives (e.g., workshops, presentations, and conference attendance).

5.5. CIHR Completed Summary

Although currently a minority in long-term care (LTC) settings, researchers predict an increase in the commonality of married couples relocating to LTC together due to increased longevity and the likelihood of age-related health declines and disability (Milan et al., 2014; Gladstone, 1992). Research reveals that couple’s collective relocation to LTC is fueled by their strong aspirations and marital commitments to stay together (Kemp, 2008, 2012). However, institutional practices in British Columbia (B.C.) invoke the separation of married couples in LTC settings, such as having one spouse reside in assisted living (AL) or independent living (IL), and the other with more complex care needs (such as persons with dementia) reside in LTC. The purpose of this study is to examine couples' abilities and challenges in maintaining the quality of their relationship when separated in LTC settings as a result of one spouse living with dementia. In addition, investigating how the separation of couples influences both spouses' overall health and well-being and how the socio-physical environment of LTC settings influences couples’ abilities to maintain their sense of couplehood.

Couplehood has emerged as an important concept in dementia literature (Evans & Lee, 2014). Defined as "the relationship between two committed individuals, characterized by a sense of…shared identity, a sense of purpose, and commitment", it has been found that despite the multitude of emotional losses associated with dementia, that spouses can maintain the quality of their relationship and a strong sense of commitment to their partner (Kaplan, 2001; McGovern, 2012, p. 5; Hellstrom et al., 2005, 2007). The continuity of marital relationships when both spouses reside in LTC settings has yet to be focused on in research. Although there is considerable literature that explores the impacts of separation and the socio-physical environment of LTC on visiting spouses' (still community-dwelling) abilities to maintain their sense of couplehood, the examination of couples' challenges when both spouses reside in an LTC setting is non-existent. Additionally, there is a current lack of research that addresses the perceptions of both spouses (i.e., the caregiving spouse and the spouse with dementia), thus, disregarding both spouse's experiences. This is imperative when focusing on research that is exploring the relationships of couples itself. This omission presents a significant knowledge gap. It neglects a core characteristic of person-centred/person-directed care practices, maintaining familial bonds and including family in care (Alzheimer’s Society of British Columbia, 2011).

The proposed study adopts a qualitative research design with two components. The first consists of face-to-face semi-structured interviews with 10-15 couples at 4-6 LTC or Assisted/Independent Living facilities (one spouse may live in either) in Metro Vancouver, B.C. Recognizing the paucity of research that examines the impacts of spousal separation on persons with dementia and their subjective experiences, interviews will be completed with both spouses, including those with dementia. This will result in a total number of 20-30 interviews. Interviews will gain insight into the lived experiences of older couples separated in LTC settings and how their separation has impacted their relationship and each spouse's health and well-being. The second involves conducting focus groups with care staff, specifically nurses and personal support workers at the 4-6 LTC or Assisted/Independent Living facilities who have married couples as residents. Each focus group will consist of 5-10 care staff. Supplementing interview data with care staff focus groups will achieve a deeper understanding of the socio-physio environmental features (e.g., layout, the culture of care/intuitional protocols and practices, and staff understanding) that challenge couples' abilities to maintain their relationship. Both resident couples and care staff participants will be recruited with aid from contacted LTC home executive directors. After consenting for their home's participation, executive directors will identify and contact care home staff who will aid in selecting resident couples as well as recruit interested care staff. The identified care staff will also act as a liaison between the research team and participating couples. The participating homes will also serve as important collaborators for knowledge translation, aiding in disseminating findings and ideally piloting recommended supportive interventions and practices.

This research will be valuable because it will critically evaluate the procedures and culture of care that impact a couple's abilities to maintain their relationship. In particular, the funded research will be highly instrumental in the refinement of existing policies and the development of innovative initiatives that will support a couple's emotional needs and improve and/or sustain their overall health and quality of life in LTC settings.

References

Aged Care Online. (n.d.). *Group Homes Australia Residential*. Retrieved August 12, 2021, from https://agedcareonline.com.au/residential-aged-care/facilities/group-homes-australia

Aged Care Online. (2017). *Group Homes Australia's Unique Aged Care Model Keeping Couples Together*. https://agedcareonline.com.au/2017/02/Group-Homes-Australia-Keeping-Couples-Together

Albuquerque, D. da S., Amancio, D. A. R., Günther, I. de A., & Higuchi, M. I. G. (2018). Theoretical contributions on aging from the perspective of person-environment studies. *Psicologia USP*, *29*(3), 442–448. https://doi.org/10.1590/0103-656420180142

Alzheimer's Society. (2020). *Face to face 1-2-1 conversation or interviews*. https://www.alzheimers.org.uk/dementia-professionals/dementia-experience-toolkit/research-methods/conversation-or-interviews

Alzheimer's Society of British Columbia. (2011). *Guidelines for Care: Person-centred care of people with dementia living in care homes*.

Alzheimer Society of Canada. (2020). *What is dementia?* Retrieved June 20, 2021, from https://alzheimer.ca/en/about-dementia/what-dementia

Alzheimer Society of Canada. (2018). *Latest information and statistics*. https://alzheimer.ca/en/Home/Get-involved/Advocacy/Latest-info-stats

Andel, R., Hyer, K., & Slack, A. (2007). Risk factors for nursing home placement in older adults with and without dementia. *Journal of Aging and Health*, *19*(2), 213–228. https://doi.org/10.1177/0898264307299359

Arbel, I., Bingham, K. S., & Dawson, D. R. (2019). A Scoping Review of Literature on Sex and Gender Differences Among Dementia Spousal Caregivers. *The Gerontologist*, *59*(6), 802–815. https://doi.org/10.1093/geront/gny177

Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology: Theory and Practice*, *8*(1), 19–32. https://doi.org/10.1080/1364557032000119616

Armstrong, P., & Braedley, S. (2016). *Physical Environments for Long-term Care Ideas Worth Sharing*. RR Donnelley.

Bernard, M., & Rowles, G. D. (2012). The Meaning of Place in Residential and Public Spaces. In *Environmental Gerontology: Making Meaningful Places in Old Age* (Issue 2012, pp. 1–24). ProQuest Ebook Central.

Bharucha, A. J., Pandav, R., Shen, C., Dodge, H. H., & Ganguli, M. (2004). Predictors of Nursing Facility Admission: A 12-Year Epidemiological Study in the United States. *Journal of the American Geriatrics Society*, *52*(3), 434–439. https://doi.org/10.1111/j.1532-5415.2004.52118.x

Bielsten, T., & Hellström, I. (2019). An extended review of couple-centred interventions in dementia: Exploring the what and why-Part B. *Dementia*, *18*(8), 2450–2473. https://doi.org/10.1177/1471301217737653

Bradley, J. M., & Cafferty, T. P. (2001). Attachment among older adults: Current issues and directions for future research. *Attachment and Human Development*, *3*(2), 200–221. https://doi.org/10.1080/14616730126485

Braithwaite, D. O. (2002). “Married Widowhood”: Maintaining couplehood when one spouse is living in a nursing home. *Southern Communication Journal*, *67*(2), 160–179. https://doi.org/10.1080/10417940209373227

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. http://dx.doi.org/10.1191/1478088706qp063oa

Brinkmann, S. (2007). The Good Qualitative Researcher. *Qualitative Research in Psychology*, *4*(1–2), 127–144. https://doi.org/10.1080/14780880701473516

British Columbia Ministry of Health. (2019). *Home and Community Care Policy Manual.* https://www2.gov.bc.ca/assets/gov/health-safety/home-community-care/accountability/hcc-policy-manual/6_hcc_policy_manual_chapter_6.pdf

Brownie, S., Horstmanshof, L., & Garbutt, R. (2014). Factors that impact residents’ transition and psychological adjustment to long-term aged care: A systematic literature review. *International Journal of Nursing Studies*, *51*(12), 1654–1666. https://doi.org/10.1016/j.ijnurstu.2014.04.011

Buhr, G. T., Kuchibhatla, M., & Clipp, E. C. (2006). Caregivers’ Reasons for Nursing Home Placement: Clues for Improving Discussions With Families Prior to the Transition. *The Gerontologist*, *46*(1), 52–61. https://academic.oup.com/gerontologist/article/46/1/52/566752

Canadain Centre for Elder Law. (2019). *Conversations about Care: The Law and Practice of Health Care Consent for People Living with Dementia in British Columbia*. https://www.bcli.org/wordpress/wp-content/uploads/2019/02/HCC_summary-Report_web_v2.pdf

Canadian Insitute of Health Research (CIHR). (2016). *About us - CIHR*. https://cihr-irsc.gc.ca/e/29418.html

Canadian Institute if Health Information (CIHI). (2018). *Dementia in long-term care.* Retrieved June 20, 2021, from https://www.cihi.ca/en/dementia-in-canada/dementia-care-across-the-health-system/dementia-in-long-term-care

Carter, N., Bryant-Lukosius, D., Dicenso, A., Blythe, J., & Neville, A. J. (2014). The use of triangulation in qualitative research. *Oncology Nursing Forum*, *41*(5), 545–547. https://doi.org/10.1188/14.ONF.545-547

Chapman, N. J., & Carder, P. C. (2003). Privacy Needs When Visiting a Person With Alzheimer's Disease: Family and Staff Expectations. *The Journal of Applied Gerontology*, *22*(4), 506–522. https://doi.org/10.1177/0733464803254339

Charmaz, K. (2006). *Constructing grounded theory : a practical guide through qualitative analysis*. London: Sage Publications Ltd.

Charmaz, K. (2014). *Constructing grounded theory* (2nd ed.). Thousand Oakes, LA/London, England: SAGE.

Chaudhury, H., & Oswald, F. (2019). Advancing understanding of person-environment interaction in later life: One step further. *Journal of Aging Studies*, *51*, 1–9. https://doi.org/10.1016/j.jaging.2019.100821

Chircop, Y. (2017). *From "Me" to "We": The Journey of Young Married Couples' Experience towards the Co-construction of Couplehood*.

Corbin, J. M., & Strauss, A. (1990). Grounded theory research: Procedures, canons, and evaluative criteria. *Qualitative Sociology*, *13*(1), 3–21. https://doi.org/10.1007/BF00988593

Cridland, E. K., Phillipson, L., Brennan-Horley, C., & Swaffer, K. (2016). Reflections and Recommendations for Conducting In-Depth Interviews with People with Dementia. *Qualitative Health Research*, *26*(13), 1774–1786. https://doi.org/10.1177/1049732316637065

Cruz, E. (2006). Elders' and Family Caregivers' Experience of Place at an Assisted Living Center. *OTJR: Occupation, Participation and Health*, *26*(3), 97–107.

De Vries, K., & McChrystal, J. (2010). Using attachment theory to improve the care of people with dementia. *International Journal of Work Organisation and Emotion*, *3*(3), 287–301. https://doi.org/10.1504/IJWOE.2010.032927

Dewing, J. (2007). Participatory research: A method for process consent with persons who have dementia. *Dementia*, *6*(1), 11–25. https://doi.org/10.1177/1471301207075625

Dewing, J. (2008). Process Consent and Research with Older Persons Living with Dementia. *Research Ethics Review*, *4*(2), 59–64.

Evans, D., & Lee, E. (2014). Impact of dementia on marriage: A qualitative systematic review. *Dementia*, *13*(3), 330–349. https://doi.org/10.1177/1471301212473882

Family Law Act, SBC 2011, c. 25, s.1(3). Retrieved from: http://www.bclaws.ca/EPLibraries/bclaws_new/document/ID/freeside/00_11025_01

Farquhar, J., & Michels, N. (2016). *Triangulation without Tears, Marketing Challenges in a Turbulent Business Environment* (Issue 3). Springer.

Førsund, L., & Ytrehus, S. (2018). Finding a place to connect: A qualitative study exploring the influences of the physical and social environments on spouses' opportunities to maintain relationships when visiting a partner with dementia living in long-term care. *Dementia*, *17*(7), 858–879. https://doi.org/10.1177/1471301216656087

Førsund, L. (2017). *Doctoral thesis Dementia in spousal relationships - Exploring the views of spouses of partners Linn Hege Førsund Dementia in spousal relationships - Exploring the views of spouses of partners* (Vol. 6). Norwegian University of Science and Technology.

Førsund, L., Skovdahl, K., Kiik, R., & Ytrehus, S. (2015). The loss of a shared lifetime: A qualitative study exploring spouses' experiences of losing couplehood with their partner with dementia living in institutional care. *Journal of Clinical Nursing*, *24*(1–2), 121–130. https://doi.org/10.1111/jocn.12648

Førsund, L., Kiik, R., Skovdahl, K., & Ytrehus, S. (2016). Constructing togetherness throughout the phases of dementia: a qualitative study exploring how spouses maintain relationships with partners with dementia who live in institutional care. *Journal of Clinical Nursing*, *25*, 3010–3025. https://doi.org/10.1111/jocn.13320

Friedman, S. M., Steinwachs, D. M., Rathouz, P. J., Burton, L. C., & Mukamel, D. B. (2005). Characteristics predicting nursing home admission in the program of all-inclusive care for elderly people. *Gerontologist*, *45*(2), 157–166. https://doi.org/10.1093/geront/45.2.157

Funk, L. M. (2019). Caregiver Identity. In D. Gu & M. E. Dupre (Eds.), *Encyclopedia of Gerontology and Population Aging* (pp. 1–5). Springer, Cham. https://doi.org/10.1007/978-3-319-69892-2_6-1

Funk, L., & Stajduhar, K. (2009). Interviewing family caregivers: Implications of the caregiving context for the research interview. *Qualitative Health Research*, *19*(6), 859–867. https://doi.org/10.1177/1049732309334105

Gladstone, J. W. (1992). Identifying the Living Arrangements of Elderly Married Couples in Long-term Care Institutions. *Canadian Journal on Aging / La Revue Canadienne Du Vieillissement*, *11*(2), 184–196. https://doi.org/10.1017/S0714980800011715

Gladstone, J. W. (1995a). Elderly Married Persons Living in Long Term Care Institutions: A Qualitative Analysis of Feelings. *Ageing and Society*, *15*(4), 493–513. https://doi.org/10.1017/S0144686X00002877

Gladstone, J. W. (1995b). The Marital Perceptions of Eldely Persons Living or Having a Spouse Living in a Long-term Care Institution in Canada. *The Gerontologist*, *35*(1), 52–60.

Glasier, W. C. (2016). “Torn apart”: Involuntary separation and the search for connection. In *ProQuest Dissertations and Theses* (Issue June). https://search.proquest.com/docview/1829545312?accountid=10957%0Ahttp://www.redi-bw.de/links/unifm?url_ver=Z39.88-2004&rft_val_fmt=info:ofi/fmt:kev:mtx:dissertation&genre=dissertations+&+theses&sid=ProQ:ProQuest+Dissertations+&+Theses+Global&atitle=&tit

Glasier, W. C., & Arbeau, K. J. (2019). Caregiving Spouses and the Experience of Involuntary Separation. *Gerontologist*, *59*(3), 465–473. https://doi.org/10.1093/geront/gnx163

Government of British Columbia. (2016). *Accommodating Spouses in Assisted Living and Residential Care - Province of British Columbia*. https://www2.gov.bc.ca/gov/content/family-social-supports/seniors/about-seniorsbc/seniors-action-plan/what-we-ve-done/accommodating-spouses-in-assisted-living-and-residential-care

Government of British Columbia. (2020). *Long-Term Care Services*. https://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/care-options-and-cost/long-term-care-services

Harman, G., & Clare, L. (2006). Illness Representations and Lived Experience in Early-Stage Dementia. *Qualitative Health Research*, *16*(4), 484–502. https://doi.org/10.1177/1049732306286851

Harrefors, C., Sävenstedt, S., & Axelsson, K. (2009). Elderly people’s perceptions of how they want to be cared for: An interview study with healthy elderly couples in Northern Sweden. *Scandinavian Journal of Caring Sciences*, *23*(2), 353–360. https://doi.org/10.1111/j.1471-6712.2008.00629.x

Heliker, D., & Scholler-Jaquish, A. (2006). Transition of new residents to long-term care: basing practice on residents’ perspective. *Journal of Gerontological Nursing*, *32*(9), 34–42. http://myaccess.library.utoronto.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=2009280117&site=ehost-live

Hellström, I., Nolan, M., & Lundh, U. (2005). ‘We do things together’:A case study of ‘couplehood’ in dementia. *Dementia*, *4*(1), 7–22. https://doi.org/10.1177/1471301205049188

Hellström, I., Nolan, M., & Lundh, U. (2007). Sustaining “couplehood” Spouses’ strategies for living positively with dementia. *Dementia*, *6*(3), 383–409. https://doi.org/10.1177/1471301207081571

Hemingway, D., Maccourt, P., Pierce, J., & Strudsholm, T. (2016). Together but apart: Caring for a spouse with dementia resident in a care facility. *Dementia*, *15*(4), 872–890. https://doi.org/10.1177/1471301214542837

Hennings, J., & Froggatt, K. (2019). The experiences of family caregivers of people with advanced dementia living in nursing homes, with a specific focus on spouses: A narrative literature review. *Dementia*, *18*(1), 303–322. https://doi.org/10.1177/1471301216671418

Hennings, J., Froggatt, K., & Payne, S. (2013). Spouse caregivers of people with advanced dementia in nursing homes: A longitudinal narrative study. *Palliative Medicine*, *27*(7), 683–691. https://doi.org/10.1177/0269216313479685

Hernandez, E., Spencer, B., Ingersoll-Dayton, B., Faber, A., & Ewert, A. (2019). “We are a Team”: Couple Identity and Memory Loss. *Dementia*. https://doi.org/10.1177/1471301217709604

Hesse-Biber, S., & Leavy, P. (2006). *The Practice of Qualitative Research*. Thousand Oaks : SAGE Publications.

Høgsnes, L., Melin-Johansson, C., Norbergh, K. G., & Danielson, E. (2013). Aging & Mental Health The existential life situations of spouses of persons with dementia before and after relocating to a nursing home The existential life situations of spouses of persons with dementia before and after relocating to a nursing home. *Aging & Mental Health*, *18*(2), 152–160. https://doi.org/10.1080/13607863.2013.818100

Howe, E. (2012). Informed Consent, Participation in Research, and the Alzheimer’s Patient. *Innovations in Clinical Neuroscience*, *9*(5–6), 47–51.

Hubbard, G., Downs, M. G., Tester, & S., & Tester, S. (2003). Including older people with dementia in research: Challenges and strategies. *Aging and Mental Health*, *7*(5), 351–362. https://doi.org/10.1080/1360786031000150685

Hunt, B. (2015). *The Emotional Impact on Elderly Spouses Who Placed Their Loved Ones in Long-Term*. https://scholarworks.waldenu.edu/dissertations

Ingebretsen, R., & Solem, P. E. (2009). Spouses of persons with dementia: Attachment, loss and coping. *Norwegian Journal of Epidemiology*, *8*(2), 149–156. https://doi.org/10.5324/nje.v8i2.457

Jungers, C. M. (2010). Leaving Home : An Examination of Late-Life Relocation Among Older Adults. *Journal of Counseling and Development: JCD*, *88*(4), 416–424.

Kane, L. (2016). *Long-married couple living in different B.C. care homes grieves separation - The Globe and Mail*. The Globe and Mail. https://www.theglobeandmail.com/news/british-columbia/long-married-couple-living-in-different-bc-care-homes-grieve-separation/article31585631/

Kaplan, L. (2001). *A Couplehood Typology for Spouses of Institutionalized Persons with Alzheimer ' s Disease : Perceptions of " We " - " I " Published by : National Council on Family Relations Stable URL : http://www.jstor.org/stable/585778 Linked references are available o*. *50*(1), 87–98.

Kemp, C. L. (2008). Negotiating transitions in later life: Married couples in assisted living. *Journal of Applied Gerontology*, *27*(3), 231–251. https://doi.org/10.1177/0733464807311656

Kemp, C. L. (2012). Married Couples in Assisted Living: Adult Children's Experiences Providing Support. *Journal of Family Issues*, *33*(5), 639–661. https://doi.org/10.1177/0192513X11416447

Kemp, C. L., Ball, M. M., Perkins, M. M., & Bowers, B. J. (2016). Couples' Social Careers in Assisted Living: Reconciling Individual and Shared Situations. *The Gerontologist*, *56*(5), 841–854. https://doi.org/10.1093/geront/gnv025

Koppitz, A. L., Dreizler, J., Altherr, J., Bosshard, G., Naef, R., & Imhof, L. (2017). Relocation experiences with unplanned admission to a nursing home: A qualitative study. *International Psychogeriatrics*, *29*(3), 517–527. https://doi.org/10.1017/S1041610216001964

Lambert, S. D., & Loiselle, C. G. (2008). Combining individual interviews and focus groups to enhance data richness. *Journal of Advanced Nursing*, *62*(2), 228–237. https://doi.org/10.1111/j.1365-2648.2007.04559.x

Lawton, M. P., & Nahemow, L. (1973). Ecology and the aging process. *The Psychology of Adult Development and Aging.*, 619–674. https://doi.org/10.1037/10044-020

Lepore, M., Shuman, S. B., Wiener, J. M., & Gould, E. (2017). *Challenges in Involving People with Dementia as Study Participants in Research on Care and Services Background Paper*. https://aspe.hhs.gov/national-alzheimers-project-act

Levac, D., Colquhoun, H., & O'Brien, K. K. (2010). Scoping studies: Advancing the methodology. *Implementation Science*, *5*(1), 1–9. https://doi.org/10.1186/1748-5908-5-69

Liamputtong, P. (2015). Focus Group Methodology and Practical Considerations. In *Focus Group Methodology: Principles and Practice*. https://doi.org/10.4135/9781473957657.n4

Lockwood, C., Borgess dos Santos, K., & Pap, R. (2019). Practical Guidance for Knowledge Synthesis: Scoping Review Methods. *Asian Nursing Research*, *13*(5), 287–294. https://doi.org/10.1016/j.anr.2019.11.002

Maguire, M., & Delahunt, B. (2017). Doing a thematic analysis: A practical, step-by-step guide for learning and teaching scholars. *AISHE-J - The All Ireland Journal of Teaching and Learning in Higher Education*, *9*(3).

Malone, M. (2016). *“All The Power To Them”: Exploring Perspectives And Experiences Of Intimacy And Sexuality Among Older Long-Term Care Residents*. Dalhousie Univeristy.

Mazaheri, M., Eriksson, L. E., Heikkilä, K., Nasrabadi, A. N., Ekman, S. L., & Sunvisson, H. (2013). Experiences of living with dementia: Qualitative content analysis of semi-structured interviews. *Journal of Clinical Nursing*, *22*(21–22), 3032–3041. https://doi.org/10.1111/jocn.12275

McGovern, J. (2012). Couplehood and the Phenomenology of Meaning for Older Couples Living with Dementia. In *New York University’s Silver School of Social Work*. https://doi.org/10.1017/CBO9781107415324.004

Migdal, A. (2020). *They’ve been married for 65 years. COVID-19 is keeping them apart | CBC News*. CBC News. https://www.cbc.ca/news/canada/british-columbia/separated-seniors-1.5620001

Milan, A., Wong, I., & Vézina, M. (2014). Emerging trends in living arrangements and conjugal unions for current and future seniors. *Statistics Canada*, 1–11. www.statcan.gc.ca,

Miller, T. G. (2016). *The Lived Experience Of Spousal Transition Within Dementia and Relocation To Long Term Care*. University of Brandon.

Miskovski, K. (2017). *Relationships and Dementia*. Alzheimer’s Australia NSW. https://www.dementia.org.au/sites/default/files/NSW/documents/Discussion%20Paper%20Relationships%20and%20Dementia.pdf

Mitchell, B. (2003). Life Course Theory. In *The International Encyclopedia of Marriage and Family Relationships* (2nd (J.J., pp. 1051–1055). New York: Macmillan Reference, USA. https://doi.org/10.2307/j.ctv1ktbdtn.7

Mitchell, B. (2016). Happily Ever After? Martial Satisfaction during Middle Adulthood years. In J. Bookwala (Ed.), *Couple Relationships in Mid and Later Life: Their Nature, Complexity, and Role in Health and Illness* (pp. 17–36). American Psychological Association.

Monin, J. K., Schulz, R., & Kershaw, T. S. (2013). Caregiving spouses attachment orientations and the physical and psychological health of individuals with Alzheimer’s disease. *Aging and Mental Health*, *17*(4), 508–516. https://doi.org/10.1080/13607863.2012.747080

Morton-Chang, F., Majumder, S., & Berta, W. (2021). Seniors’ campus continuums: local solutions for broad spectrum seniors care. *BMC Geriatrics*, *21*(1), 1–23. https://doi.org/10.1186/s12877-020-01781-8

Mullin, J., Simpson, J., & Froggatt, K. (2011). Experiences of spouses of people with dementia in long-term care. *Dementia*, *12*(2), 177–191. https://doi.org/10.1177/1471301211418096

Nagle, B., & Williams, N. (2020). *Methodology Brief: Introduction to Focus Groups*. http://www.mmgconnect.com/projects/userfiles/file/focusgroupbrief.pdf

National Institute on Ageing. (2019). *Enabling the Future Provision of Long-Term Care in Canada*. https://static1.squarespace.com/static/5c2fa7b03917eed9b5a436d8/t/5d9de15a38dca21e46009548/1570627931078/Enabling+the+Future+Provision+of+Long-Term+Care+in+Canada.pdf

Nyumba, T., Wilson, K., Derrick, C. J., & Mukherjee, N. (2018). The use of focus group discussion methodology: Insights from two decades of application in conservation. *Methods in Ecology and Evolution*, *9*(1), 20–32. https://doi.org/10.1111/2041-210X.12860

Office of the Seniors Advocate of British Columbia [B.C]. (2020). *Staying Apart To Stay Safe: The Impact of Visit Restrictions on Long-Term Care and Assisted Living Survey*. https://www.seniorsadvocatebc.ca/app/uploads/sites/4/2020/11/StayingApartToStaySafe-Report.pdf

Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research. *Administration and Policy in Mental Health and Mental Health Services Research*, *42*(5), 533–544. https://doi.org/10.1007/s10488-013-0528-y

Patton, M. Q. (2015). Qualitative research & evaluation methods : integrating theory and practice. In *Qualitative research and evaluation methods* (4th ed.). Thousand Oaks, California : SAGE Publications, Inc.

Perlesz, A., & Lindsay, & J. (2003). Methodological triangulation in researching families: Making sense of dissonant data. *International Journal of Social Research Methodology*, *6*(1), 25–40. https://doi.org/10.1080/13645570305056

Pham, M. T., Rajić, A., Greig, J. D., Sargeant, J. M., Papadopoulos, A., & Mcewen, S. A. (2014). A scoping review of scoping reviews: Advancing the approach and enhancing the consistency. *Research Synthesis Methods*, *5*(4), 371–385. https://doi.org/10.1002/jrsm.1123

Pittman, J. F., Keiley, M. K., Kerpelman, J. L., & Vaughn, B. E. (2011). Attachment, Identity, and Intimacy: Parallels Between Bowlby's and Erikson's Paradigms. *Journal of Family Theory & Review*, *3*(1), 32–46. https://doi.org/10.1111/j.1756-2589.2010.00079.x

Quinn, C. (2017). Conducting Interviews With People With Dementia and Their Caregivers. *SAGE Research Methods Cases in Health*, 2–13. https://doi.org/10.4135/9781526404855

Roberto, K. A., McCann, B. R., & Blieszner, R. (2013). Trajectories of care: Spouses coping with changes related to mild cognitive impairment. *Dementia*, *12*(1), 45–62. https://doi.org/10.1177/1471301211421233

Rogers-De Jong, M., & Strong, T. (2014). Co-constructing “We” and “Us” Joint talk and storytelling with cohabitating couples. *Narrative Inquiry*, *24*, 368–385. https://doi.org/10.1075/ni.24.2.10jon

Rowles, G., & Bernard, M. (2013). Long-Term Care Environments. In *Enviornmental Gerontology: Making Meaningful Places in Old Age*. Springer Publishing Company.

Sandberg, J., Lundh, U., & Nolan, M. (2001). Placing a spouse in a care home: the importance of keeping. *Journal Of Clinical Nursing*, *10*, 406–416.

Schulz, R., & Sherwood, P. R. (2008). Physical and Mental Health Effects of Family Caregiving. *Am J Nurs*, *108*(9), 23–27. https://doi.org/10.1097/01.NAJ.0000336406.45248.4c

Statistics Canada. (2011). *Living arrangements of seniors Families, households and marital status Structural type of dwelling and collectives, 2011 Census of Population*. https://doi.org/98-312-X2011003 Census

Statistics Canada. (2017). *Census of Population -Families, Households and Marital Status*. https://www12.statcan.gc.ca/census-recensement/2016/dp-pd/index-eng.cfm

Stewart, D. W., Shamdasani, N., & Rook, D. W. (2007). Analyzing Focus Group Data In: Focus Groups. In *Focus Groups Theory and Practice* (2nd Editio, pp. 109–133). https://doi.org/10.4135/9781412991841

Sucharew, H., & Macaluso, M. (2019). Methods for research evidence synthesis: The scoping review approach. *Journal of Hospital Medicine*, *14*(7), 416–418. https://doi.org/10.12788/jhm.3248

Swall, A., Williams, C., & Marmstål Hammar, L. (2019). The value of “us”—Expressions of togetherness in couples where one spouse has dementia. *International Journal of Older People Nursing*, *15*(2). https://doi.org/10.1111/opn.12299

Thomas, D. R. (2003). *A general inductive approach for qualitative data analysis*.

Tilse, C. (1994). Long Term Marriage and Long Term Care “We Thought We’d be Together till we Died.” *Australian Journal on Ageing*, *13*(4), 172–174. https://doi.org/10.1111/j.1741-6612.1994.tb00666.x

Tilse, Cheryl. (1997). She Wouldn’t Dump Me: The Purpose and Meaning of Visiting a Spouse in Residential Care. *Journal of Family Studies*, *3*(2), 196–208. https://doi.org/10.5172/jfs.3.2.196

Tilse, Cheryl. (1998). Continuing or refusing to care: The meaning of placing a spouse in long term care. *American Journal of Alzheimer's Disease*, 29–33.

Torgé, C. (2018). Whose Right to a "Reasonable Level of Living"? Spouses with Differing Care Needs in Swedish Nursing Homes. *The Journal of Aging and Social Change*, *8*(1), 45–60. https://doi.org/10.18848/2576-5310/CGP

Torgé, C. (2020). "Being in-Between": Spouses That Cohabit With and Provide Care for Their Partners in Nursing Homes. *Journal of Applied Gerontology*, *39*(4), 377–384. https://doi.org/10.1177/0733464818803007

Wadham, O., Simpson, J., Rust, J., & Murray, C. (2015). Couples' shared experiences of dementia: A meta-synthesis of the impact upon relationships and couplehood. *Aging and Mental Health*, *20*(5), 463–473. https://doi.org/10.1080/13607863.2015.1023769

Wagner, J., Voelkle, M. C., Hoppmann, C. A., Luszcz, M. A., & Gerstorf, D. (2018). We are in this together: Dyadic patterns of self-esteem change in late-life couples. *International Journal of Behavioral Development*, *42*(1), 34–42. https://doi.org/10.1177/0165025416679742

Wahl, H.-W., Iwarsson, S., & Oswald, F. (2012). The Gerontologist Aging Well and the Environment: Toward an Integrative Model and Research Agenda for the Future. *The Gerontologist*, *52*(3), 306–316. https://doi.org/10.1093/geront/gnr154

Waldinger, R. J., Cohen, S., Schulz, M. S., Crowell, J. A., Psychol, C., & Author, S. (2015). Security of attachment to spouses in late life: Concurrent and prospective links with cognitive and emotional wellbeing HHS Public Access Author manuscript. *Clin Psychol Sci*, *3*(4), 516–529. https://doi.org/10.1177/2167702614541261

Walker, R. B., & Luszcz, M. A. (2009). The health and relationship dynamics of late-life couples : a systematic review of the literature. *Ageing and Society*, *29*, 455–480. https://doi.org/10.1017/S0144686X08007903

Watterson, R. (2017). *Experiences of having a partner with dementia in long term care: A review*. Lancaster University.

Wijngaart, M., Vernooij-Dassen, M., & Felling, A. (2008). Aging & Mental Health The influence of stressors, appraisal and personal conditions on the burden of spousal caregivers of persons with dementia. *Aging & Mental Health*, *11*(6), 626–636. https://doi.org/10.1080/13607860701368463

Willoughby, B. J., Hall, S. S., & Luczak, H. (2015). Marital Paradigms: A Conceptual Framework for Marital Attitudes, Values, and Beliefs. *Article in Journal of Family Issues*, *36*(2), 188–211. https://doi.org/10.1177/0192513X13487677

Wister, A. (2019). *Aging as a Social Processes: Canada and Beyond* (7th ed.). Toronto: Oxford University Press.

Wong, S. L., Gilmour, H., & Ramage-Morin, P. L. (2016). Health Reports Alzheimer's disease and other dementias in Canada. In *Statistics Canada Health Matters*. www.statcan.gc.ca

Appendix A.

Scoping Review Article Chart

Author(s), Year, and Location	Keywords	Focus of Study	Methodology	Key Findings
Braithwaite, D. (2002). USA	N/A	Study focused on two goals, the first, was to examine the impact of role shifts for caregiving wives whose husbands relocated to a nursing home. The second, was to explore how caregiving wives see their identity as an individual as well as in their relationship in a nursing home.	Qualitative, in-depth interviews. Sample of 21 wives of husbands in nursing homes.	Key findings highlighted that a wife's role changes were significant when their partner relocated to LTC. For example, wives took on the more gendered roles associated with their husbands such as finances and physical maintenance of their homes. Also, it was found that the emotional losses associated with anticipatory grief and the feelings of being single and/or already widowed, however, still married "married widows". The need to take on new roles, often socially isolated the wives. It's important to note, that not all wives experienced the same role changes and the emotions attached, and therefore, a key finding is that there should be cautions "against seeing all spouses as alike and highlights that individuals may have different needs regarding their own role in the care of their spouse" (p. 177).
Chapman, N & Carder., (2003). USA	Alzheimer's, family, long-term care, privacy, visit	The study explored the impacts of the physical and social environment on family members' visits with a loved one with dementia in long-term care.	Qualitative research methods. Focus groups with eight family caregivers to persons living with dementia living in LTC. Interviews were conducted with 22	Findings suggested that privacy needs varied and are circumstantial, which change along with the progression of dementia. Furthermore, within LTC settings, it was found that private bedrooms afforded a stable place for private interactions. However, as their loved one's dementia progressed, semi-private places became preferred as they offered more social interaction and the availability of care staff. Family

Author(s), Year, and Location	Keywords	Focus of Study	Methodology	Key Findings
		In particular, the study focused on the challenge of privacy.	family members and 26 care staff at 15 LTC homes.	members need to redefine their sense of privacy within LTC as they adapt to the changes in their loved one's cognition. Principal challenges to privacy included invasions of personal space by other residents and staff.
Cruz., E. (2006). USA	Sense of place, assisted living, occupational form	The purpose was to investigate residents in AL and their family caregivers phenomenological experience a sense of place.	Qualitative research design. Utilized ethnographic observations in AL of residents and their family caregivers and semi-structured interviews with family caregivers and care staff. Focus groups were also performed (one with family caregivers and one with staff) as a means of member checking.	Findings indicated the principal characteristics of AL that impact residents and their family caregivers' experience of place. The socio-cultural norms and physical environment, such as the design/layout of the facility, were highlighted. The facility's cultural norms had expectations that sometimes clashed with declining health (e.g., social expectations of wearing street clothes). These cultural norms influenced family caregivers' visits in which they would aid in helping their family member 'fit in,' such as making sure they were wearing appropriate clothes. Roommates were discussed as an issue concerning privacy and the ability to personalize private bedrooms. The physical environment, such as floor plan, and distance between key areas, was revealed to have both positive and negative implications. For example, some residents and family members liked the longer length because it afforded privacy, yet others with mobility issues found the distance a challenge. Lastly, it was found that the development of a sense of community at this facility between residents, their family caregivers, and staff strengthened the development of a sense of place.
Førsund, et al., (2015). Norway	Couplehood, Dementia, Grounded	Aimed to examine spouses' experiences of	Qualitative research design.	Key findings revealed that visiting/caregiving spouses' feelings of losing couplehood was directly connected with physical separation, and in turn

Author(s), Year, and Location	Keywords	Focus of Study	Methodology	Key Findings
	theory, Interviewing, Nursing home, Spouses	couplehood when one partner has dementia and lives in LTC.	Constructivist grounded theory approach. Conversational interviews. Sample of 10 spouses.	anticipatory grief and feelings of being alone. Furthermore, connected with feelings of loss over their relationship (e.g., shared experiences and a future together). However, it was found that despite such grievances that many were able to maintain positive relationship quality with “short glimpses of connectedness, reciprocity and interdependence contributed to a feeling of couplehood, although these were only momentary” (121).
Førsund et al., (2016). Norway	Dementia, family caregiving, grounded theory, institutional care, older people, qualitative research, spousal relationships	The study aimed to investigate and describe couples' relationships when one spouse has dementia and lives in institutional care.	Qualitative research design. Utilized constructivist grounded theory. Interviews were conducted with 15 spousal caregivers (eight women and seven men) whose spouse lives with dementia and resides in institutional care. Participants after six interviews were recruited through theoretical sampling.	Findings demonstrated the various ways in which visiting spouses preserved their relationship. Three categories were revealed, the first involved regularly visiting their partner. Regular visits were shown to aid in visiting spouses' feelings of loneliness and fulfillment of their marital vows. The second showed that visiting spouses scheduled their visits when their partners were perhaps more alert to have a more meaningful visit. The last category demonstrated the challenges in interacting with a partner with progressing dementia. When a spouse's dementia progressed to a certain stage, it was discovered that most spouses would reduce the number of times they visited.
Førsund, L., (2017). Norway	N/A	The purpose of this thesis was to explore the significance of spousal relationships when	Thesis. Qualitative research design. Constructivist grounded theory approach. Seven men and eight women,	Findings demonstrated that the spouse's experiences were dominated by the dynamic experience of losing couplehood following the relocation of their partner. These experiences were connected to the physical separation from their partner, the sense of being alone and the loss of a shared past, and the inability

Author(s), Year, and Location	Keywords	Focus of Study	Methodology	Key Findings
		one spouse has dementia and lives in LTC. The study further aimed to explore the influence of the physical and social environments on couples' abilities to maintain their relationship.	from LTC homes in five different regions in Norway. Interviews and ethnographic observations.	to share a mutual future. Despite these experiences, being involved and experiencing continuity in the relationship still seemed important. To maintain continuity in their spousal relationship, the spouses constructed togetherness by facilitating situations in which they could connect with their partners. To facilitate these situations, visiting routines adapted to the progression of their partner's dementia. Opportunities for private interactions in individual rooms and proximity to care staff were highlighted as important environmental factors for maintaining their relationship.
Førsund, L., & Ytrehus, S., (2018). Norway	Qualitative research, Spouses, Dementia, Relationship, Long-term care	Aimed to explore the ways in which the physical and social environments of LTC influence caregiving spouses' opportunities to sustain their relationship with their partner who has dementia.	Qualitative research design. Sample size of 15 spouses whose partners have dementia and live in LTC. Observations of physical environments and participant observations were conducted.	Findings indicated that the LTC environment could hinder couples' opportunities for private/intimate interactions that would aid in the sustainment of their relationship. A key finding was that residents' private rooms held significance for both the visiting spouse and the resident. Private rooms allowed for spouses to exercise 'place making' and provided a place to connect privately. Couples 'place making' included having a space to display personal belonging and showcase shared experiences to create a home-like atmosphere. Common areas proved both valuable and problematic. Although visiting spouses liked to use common areas to interact with their spouse and provided peace of mind being close to care staff, aspects such as close quarters, activities, and limited seating often resulted in interruptions by other residents or staff.

Author(s), Year, and Location	Keywords	Focus of Study	Methodology	Key Findings
Gladstone, J. (1995a). Canada.	Elderly married couples; institutional relocation; long-term care	Focused on the emotions connected with spouses, both institutionalized and community-dwelling feelings towards having their partner in LTC.	Qualitative research design. Interviews of 161 married persons who is living with their spouse in LTC or has a spouse in LTC.	Findings indicate that married people feel more positively about relocation to LTC. For example, many couples were able to see the aid in their new living arrangements, such as caregiving spouses feeling relief in gaining help in seeing their spouses getting better care. Also, institutionalized spouses also reflected on the ability to have more socialization. Positive feeling themes included benefit to self, benefits to spouse, reappraisal of self as caregiver, and appraisal of institutionalization. Negative feeling themes included concern about institutionalized partner's care, tension with staff, stress associated with visiting, loss of purpose, loneliness, privacy, and the marital relationship.
Gladstone, J. (1995b). Canada.	Relocation; Continuity theory; Social support	Study aimed to gain insight into how married individuals who reside in LTC or have a spouse in LTC view their marital relationship post relocation.	Qualitative research design. Sample included 161 interviews. Data was separated into two groups, non-institutionalized spouses, and institutionalized spouses.	Findings suggest four themes for non-institutionalized spouses, “marriage as a memory”, the “illusory marriage”, the “changed marriage”, and the “unchanged or continuing marriage”. For non-institutionalized spouses, many voiced the changes in their marital relationship since LTC relocation, often referring to losses such companionship, changes in marital roles, and the many losses associated with a spouse’s cognitive impairment. For institutionalized spouses’ themes included, the “happy marriage”, “detached marriage”, and the “altered relationship”. Institutionalized spouses referred to the changes in their relationship because of new living arrangements (being separated). Furthermore, within the institution the issues of dependence and independence were highlighted.

Author(s), Year, and Location	Keywords	Focus of Study	Methodology	Key Findings
Glasier, W. (2016). Canada	Grounded theory; medical separation; involuntary separation; qualitative; basic social process; older adults; connecting	To identify and examine the social process of medical involuntary separation between spousal caregivers and their partners when one spouse moves into LTC.	Thesis. Qualitative research design. Interviews, focus groups with 17 spouse-caregivers (12 women and five men), with an average of 20 months of involuntary separation.	The findings of this study were categorized into three phases, (1) Initial news and coping, which involves feeling rushed into moving, grief, loss, guilt, and failure. (2) Adjusting to a new situation, which was described as needing to develop new routines, adjusting to the physical and social environment of care, still feeling an overwhelming emotional loss and toll, which the empathy and support of others can influence. (3) Moving forward, characterized as accepting their new reality, continued relationship with one's spouse, and continuing with their lives. These stages were shown to be overlapping and flexible, implying that the progression from one to the next was unavoidable but might occur at different times.
Glasier, W., & Arbeau., K. (2019). Canada	Involuntary separation, Giorgi, Caregivers, Lived experience	To explore the lived experiences of involuntary separation from the perspectives of spousal caregivers who placed their partner in LTC. Focusing on how the separation influenced spousal caregivers' health and well-being.	Qualitative research design, applying a psychological-phenomenological analysis to participant narratives. Interviews were conducted with ten spousal caregivers who were separated from their spouse for up to 4 years.	Key findings discovered four descriptive themes, "(1) the emotional upheaval that characterized the experience, (2) connections to social and emotional support, (3) level of access and involvement with the spouse, (4) and carrying on after the shift from the spouse-caregiver role to being involuntarily separated" (p. 467). The themes illustrated the overwhelming emotional experience of separation and the beneficial need for the opportunity to continue their relationship with their spouse.

Author(s), Year, and Location	Keywords	Focus of Study	Methodology	Key Findings
Hemingway et al, (2016). Canada	Alzheimer's disease, dementia, care facility, spousal caregiving, caregiver burden	Focused on gaining a deeper understanding of the experiences of caregiving spouses of a person living with dementia who resides in LTC.	Qualitative longitudinal exploratory study. Included interviews with spousal caregivers and focus groups with care home staff over a two-year period. Sample included 28 spousal caregivers and staff members from four different LTC homes across B.C.	One main theme "together but apart" along with four subthemes, "wedding vows", "continued caregiving", "separate lives" and "disease progression" were found. The main theme, together but apart, represents the obstacles of institutionalization for marital relationships. A key finding is that with separation due to institutionalization, caregiving spouses feel isolated not only from physical separation but also from the loss of shared experiences, identity, and spaces. Furthermore, that with the progression of the disease, spouses feel uncertainty and fear over the future and their spouses' fate. Ultimately, LTC homes provide spaces for caregiving spouses to feel vulnerable with a lack of recognition and support for their marital relationship.
Hennings at al., (2013). England	Caregiver, spouses, nursing homes, dementia, qualitative research, palliative care	This study aimed to learn more about the caregiving experiences of spousal caregivers of persons with dementia who live in LTC homes.	Qualitative research design applying longitudinal narrative inquiry. Twenty-seven interviews and seven diaries from ten spouse caregivers of persons with dementia were conducted and collected (7 women and three men).	This study revealed two groups that were highlighted in the key stories from participants, caregiving, and status. Within the caregiving group, it was revealed that many spouses struggled with the balance between visiting and continued caregiving and their own health and well-being. The second status further refers to the complex status of identity spousal caregivers feel, as they are no longer physically with their spouse, are still married, perform certain caregiving duties, and define these roles to their friends and family.

Author(s), Year, and Location	Keywords	Focus of Study	Methodology	Key Findings
Hennings, J., & Froggatt, K. (2019). England	Dementia caregiving, end of life, nursing homes, review, spouses	Aimed to examine the current literature surrounding the experiences of family caregivers who have placed their partner in LTC, with a particular focus on spouses.	Narrative literature review. Review of 12 articles.	Findings identified four themes (1) Changing relationships (2) the need for companionship (3) adjusting to new roles and relationships (4) anticipating death/looking towards the future. For spouses, the two themes of (1) changing identity- feelings married, being married and (2) alone but..., which reflected spouses' feelings of changing identity in their partner's dementia and separation when placed in care. The review demonstrated that spousal caregiving relationships could have distinct differences from other family caregiving relationships. Furthermore, although many changes can be negative, being in a caregiving relationship can have positivity as many expressed feeling closer to their spouse. On the other hand, tensions between care staff and spousal caregivers can arise when spouse's surveillance and intervene in care.
Høgsnes et al., (2013). Sweden	Dementia; existential, nursing homes, spouses	To investigate and characterize the existential living situations of spouses of persons with dementia before and after placing their partner in LTC.	Qualitative research design. Interviews with 11 spouses of persons with dementia. Interpretive content analysis.	Results indicated that before LTC placement, spousal caregivers exhibited feelings of guilt and social isolation. However, after placing their loved ones in care, spousal caregivers struggled with feelings of grief, guilt, and relief. Furthermore, their separation fueled feelings of loneliness over the loss of their relationship.

Author(s), Year, and Location	Keywords	Focus of Study	Methodology	Key Findings
Hunt, B. (2015). USA	Long term care; Separation; Spousal caregiving; Emotional impact	Focused on exploring the impacts of placing a spouse in LTC, and how the separation emotionally effects spousal caregivers.	Thesis. Qualitative research design. Sample of 11 community dwelling spouses whose partner resides in LTC. Couples needed to be married at least 30 years to qualify.	Five themes were discovered, "Reduction of Friends", "Ease or Difficulty with Change", "Companionship", "Vows are forever and Why"? It was evident from the findings that each of the community dwelling spouses were committed to maintain their relationship with their spouse, often visiting twice daily and remaining with their spouse for hours. Furthermore, that male caregiving spouses struggled more with anxiety and loss then their female counterparts were heightened with their assumption of new roles such as home making duties. Loss of companionship proved to be a significant emotional loss for caregiving spouses, these feelings were heightened with the emotions of isolation due to caregiving and loss of friends.
Kaplan, L. (2001). USA	Community-dwelling spouses; Couplehood; Institutionalization; typology; We-I	Aimed to discover the level caregiving/ community dwelling spouses identify with marriage when one spouse resides in LTC.	Qualitative research design. Symbolic interactionism. In-depth interviews. Sample of 71 caregiving/community dwelling spouses of persons living with dementia.	Five typologies' groups were found that represented strong feelings of "we" to feelings of "I". (a) "Till death do us part", (b) "We, but…", (c) "Husbandless wives and wifeless husbands", (d) "Becoming an I", and (e) "Unmarried marrieds". The five typologies demonstrate the subjectivity surrounding having a spouse with dementia and gives influential insight into the marital relationship. The author notes that couple's relationship prior to dementia diagnosis influences couplehood.
Kemp, C., (2008). USA	Assisted living; Health transitions; Later-life couples; Relocation	Focused on the reasons for couple's collective relocation and their experiences in AL.	Qualitative research design. Interviews with 20 married couples living together in AL.	Notes that couples' ways to and experiences in AL are circumstantial/variable. It was found that couples' collective relocation was either based on synchronous (both spouses had health declines at similar rates) or asynchronous health status (one spouse had more progressive health declines than

Author(s), Year, and Location	Keywords	Focus of Study	Methodology	Key Findings
				the other). More couples experienced asynchronous health declines, and thus, relocation was based on the couple's desires to remain together, and that the caregiving spouse moved into AL for the sake of their spouse. Furthermore, that marital commitments and the love for each other are at the foreground of the couple's aspirations to be together, and that was a predictor of subjective well-being in both partners. Lastly, a spouse's presence in AL can impact each spouse's social integration and interactions with others.
Kemp, C., Ball., M., & Perkins., M, (2016). USA	Couples, Long-term care, Intimate relationships, Social relationships, Assisted living facilities, Qualitative analysis: Grounded Theory	To gain an understanding how the marital relationship impacts social relationships in AL and create an explanatory theory.	Qualitative research design. Grounded theory. Participant observation and interviews. Sample size of 29 couples, 26 married and 3 unmarried.	Findings of this study suggest that within AL couples' social interactions with each other and others varied depending on the spouse's previous relationship quality and health status (e.g., presence of dementia). Strengths and burdens of late life couplehood were also revealed, specifically within the central theme of "reconciling individual and shared situations across time," which highlights the interconnection of couples' lives within "interpersonal and micro-level processes" (p. 854). Some couples experienced jealousy and marital infidelity due to the social environment, which resulted in the possibility of other partners. Study shows that supporting couples needs in AL need to focus on both individuals and shared health and emotional needs of couples.

Author(s), Year, and Location	Keywords	Focus of Study	Methodology	Key Findings
Malone (2016) Canada	N/A	Aimed to explore LTC residents' experiences and perspectives of sexuality and intimacy.	Thesis. Qualitative research design. In-depth interviews with 10 LTC residents (including those with dementia) at one LTC home.	Marital relationships and relationships with persons with dementia were highlighted. Both individual and system-level barriers were explored. Findings demonstrated the subjectivity of definitions of intimacy and sexuality in later life. Being married was found to have permitted more openness of sexual expression as some facilities would create private space for them to visit with each other. It was also more accepted for married couples to share a bed together. The presence of dementia was further demonstrated to both a barrier and an advantage in sexual expression in LTC. Barriers such as facility design (e.g., roommates, lack of privacy), the culture of care/staff perceptions, care practices, other residents/staff values and discrimination towards sexuality identity were demonstrated to hinder sexual expression.
Miller, T. (2016). Canada	N/A	Aimed to understand older couples experience transitioning to LTC, when one spouse has dementia.	Thesis. This qualitative research designs. Interviews with spousal caregivers.	Three themes were discovered (1) leading up to relocation, (2) managing the relocation (3) adjusting to life after relocation. The themes reveal the experience of the spousal caregiver as well as highlight how these transitions impact the couple as a unit. It was found that throughout the progression of dementia and transition to LTC, couples attempted to normalize and adapt and that although the dynamics of their relationship have changed, they experienced a sense of couplehood. However, noting that their relationship before their partner's dementia is a determining factor. Partners' relocation to LTC further sparked feelings of guilt and grief for spousal caregivers. As a unit, relocation was the most

Author(s), Year, and Location	Keywords	Focus of Study	Methodology	Key Findings
				disruptive transition, as many spousal caregivers needed to adjust to not being their partner's primary caregiver. Visiting was demonstrated to ease the transition and emotional consequences and enabled them to continue their relationship.
Miskovski, K. (2017). Australia	N/A	This paper focused on the changes in the relationship between persons living with dementia and their carer/s. Furthermore, this paper aimed to give voice to persons living with dementia.	Discussion paper. Qualitative mixed method research which utilized an online survey (193 responses- 176 carers and 17 persons living with dementia,) telephone interviews, and follow-up emails with 32 participants.	Study findings concentrated on four themes, (1) role and identity, (2) emotional and physical intimacy, (3) grief and loss (4) positive impacts. The first demonstrated how dementia could impact both carers and persons living with dementia sense of identity. For example, persons with dementia experience loss of independence and responsibility, and spouses caring for their partner may feel more in the role of a parent rather than a spouse. Second, loss of emotional and physical intimacy was found to challenge relationship quality, especially in a facility. Within a facility, it was found that staff play an influential role in facilitating space for intimacy. Grief and loss were underlined concerning the loss of their shared life together, and as a result, some develop anger and resentment towards the person with dementia. Finally, the positive features of their relationship and caregiving were highlighted. For example, dementia had given some people the chance to reconnect with loved ones and form new bonds within the dynamics of their caregiving relationship.
Mullin, J., Simpson, J., &	Dementia, Interpretative phenomenological	Focused on exploring the experiences of spouses of persons	Qualitative research design. Interpretative phenomenological	Four themes were discovered, 'identity: 'till death us do part', 'making sense of change' emphasized, 'relationship with care provided: visiting as surveillance', and 'relationship to the future: hope

Author(s), Year, and Location	Keywords	Focus of Study	Methodology	Key Findings
Froggatt, K. (2011). England	analysis, Long-term care, Spouses	with dementia who reside in LTC.	analysis. Semi-structured interviews. Sample included 10 spouses of people with dementia in LTC.	versus despair'. These themes revealed both positive and negative attributes with being a caregiving spouse to a person with dementia. Thus, highlighting those improvements in dementia care will allow for better relationship quality in LTC settings.
Sandberg, J., Lundh, U., & Nolan, M. (2001). Sweden	Care homes, placement, spouse's experience; staff-family relationships.	This study aimed to explore the lived experiences of spouses who placed their partner in LTC, and the process of relocating partners to LTC.	Qualitative research design. Grounded theory. Interviews with 14 spouses (11 wives and three husbands).	Key findings highlight the multiple different reasons one might choose to place their spouse in LTC. Furthermore, that many spouses attempt to sustain the connection with their spouse through various 'keeping activities' (e.g., visitation, partaking in activities of the home, etc.). It was also found that in attempts to sustain their relationship they wanted to 'keep staff sweet' meaning staying on good terms with them before intervening in care. The relationship between staff and caregiving spouses was further demonstrated to be complex.
Tilse, C. (1994). Australia	N/A	Aimed to gain insight into spouse's experiences of placing partners in LTC as well as examine the relationship between care staff and visiting spouses.	Qualitative research design. Interviews with spouses who placed their spouse in LTC, observations of homes programs and how visiting spouses interacted with their partners, and interviews with 72 staff members.	Key findings revealed that for caregiving spouses, placing their partner in LTC was accompanied by multiple emotional, social, and financial changes (E.g., identity, living arrangements, expressions of love, and what consists as the 'duties' of long-term marriage). For visiting spouses, visiting meant a connection to their pervious life and identity in marriage, as well as served as a way to combat loneliness and continue to care for their partners. It was also found that, care staff often failed to recognize the relationship of marriage for visiting spouses and often varied in capacity to include spouses in support or care.

Author(s), Year, and Location	Keywords	Focus of Study	Methodology	Key Findings
Tilse, C. (1997). Australia	Residential care, participation, visiting, spouse carers, and qualitative method	Aimed to investigate the experiences of spouses who have placed their partner in LTC, as well as the purpose and meaning of their visits.	Qualitative research design. In-depth interviews with 18 spouses (nine men and nine women) who had recently placed a partner in residential care 18 months prior.	Couples in long-term relationships may lose their sense of shared identity, according to the findings. As a result, a spouse's move to LTC can cause feelings of sadness and loss. It was further revealed that many spouses were torn between wanting to continue providing care with respite. Thus, visiting was also demonstrated to be a valuable means to continue caregiving and advocate for care quality.
Tilse, C. (1998). Australia	N/A	Focuses on the experience of placing and visiting a spouse with dementia in LTC.	Qualitative research design. Interviewed 18 spouses who placed their partner in LTC.	Findings revealed that placing a spouse with dementia in LTC is a complex experience. The behavioural changes of persons living with dementia were demonstrated to be the primary motivator for LTC placement. Spouses expressed feelings of guilt resulting from placing their partner in care since the decision could not be made as a unit. The actual moving day and realization of their separation was further noted as a 'traumatic experience.' Visiting was shown to be important for continuity in their relationship; however, it was also proved challenging because of the deterioration of their partner's cognitive abilities. The experience of visiting was further shown to be complicated by interactions with care staff.

Author(s), Year, and Location	Keywords	Focus of Study	Methodology	Key Findings
Torgé, J. (2018). Sweden	Residential Care; Couple; Cohabitation Introduction	The aim is to critically examine the Swedish legislation called the ‘cohabitation guarantee,’ which requires nursing homes to allow spouses with different care needs to live together.	Qualitative research design. Utilized data from a previous study involving field observations and interviews at five nursing homes in Sweden over three years. Two homes as case studies. Six interviews over a four-week observation period were conducted. Interviews with one couple, three nurse assistants in a focus group, one interview with a nursing home manager.	Findings illustrated that each municipality in Sweden could dictate how their home is organized and determine how the cohabitation guarantee is implemented. Spousal caregivers' role was found to be categorized into two perspectives' legitimate need' and 'own right.' These viewpoints were shown to influence spousal caregivers' care and rights within the homes and how staff interacted with them. Legitimate need meant that only the sicker spouse should be provided care. This perspective posed issues in situations in which the spousal caregiver faces declines in health, which is often the case. Spousal caregivers are expected to complete care and tasks for themselves and continue caregiving for their spouses. Within the own right spousal caregivers are entitled to care and services they pay a care fee for.

Author(s), Year, and Location	Keywords	Focus of Study	Methodology	Key Findings
Torgé, J. (2020). Sweden	Nursing homes; co-resident; family; caregiving; spouse	The study focused on the experiences of cohabiting spouses and how spousal caregivers experienced their caregiving role in LTC homes. Furthermore, investigating staff perspectives.	Qualitative research design, utilizing life course perspective. Interviews with 11 couples and 15 staff members. Ethnographic observations were conducted over a four-week period.	The study revealed the overarching theme of "being in between," which indicates spousal caregivers' blurred/unfamiliar role in LTC as defined by both spousal caregivers and care staff. To illustrate, spousal caregivers described being divided between being a resident themselves and a caregiver to their partners. Furthermore, while many staff were conflicted with the role of spousal caregivers in LTC, such as viewing them as useful and expecting them to complete specific care tasks for their partners. Spousal caregivers also expressed this conflict as they wished to have respite; however, they were constantly present with their partners and were torn with 'letting go' of providing care. On the other hand, many staff also empathized with spousal caregivers and wished to provide relief and care.
Watterson, R. (2017). England	Dementia; interpretative phenomenological analysis; long term care; partner	Literature review that aimed to examine the experiences of spouses whose partner is living with dementia is lives in LTC.	Literature review. Meta-synthesis involving 13 articles. The articles were synthesized and interpreted utilizing a meta-ethnographic approach. Conducted in 2016.	The review found four themes and central concepts: (1) a continuation of social isolation, (2) challenges to planning for the future, (3) embracing the changing boundaries of marriage, and (4) negotiating a new sense of self. The themes reflected how spousal caregivers' social relationships had changed since their spouse relocated to LTC (e.g., isolation) and the emotional losses they experience (guilt, grief over the loss of a future with their spouse). Additionally, the review highlighted the importance of maintaining identity in marriage and spousal caregivers' abilities/strategies of coping with the changes in their partner's dementia and their relationship. Lastly, their relationship with care home staff was too emphasized.

Appendix B.

Interview Guide: Spousal Caregivers

Thank you so much for agreeing to participate in this study about couples in care homes. This research project aims to examine couples' abilities and challenges to maintain the quality of their relationship when separated in care settings and investigate how separation influences both spouses' overall health and well-being.

I will begin by asking some background information questions.

Background Information

1. Name: ______________________
2. D.O.B: ______________ Age at time of interview: ________
3. Gender: ☐ Male ☐ Female ☐ Other: ________
4. Name of LTC Setting: ____
   Type: _____________________________ Date of Admission: ______________
5. Spouse/Partner's name: ______________ Date of Admission: ______________
6. Spouse/Partner's D.O.B: ________________ Age at time of Interview: ________
7. Name of LTC/AL Setting of spouse/partner: _____________________________
8. How would you define your relationship? (Married, common law, other)
9. Number of years together/married: _______
10. What is you and your spouse/partner's current living arrangement?

    ☐ Live in same facility

    ☐ Same facility complex

    ☐ Separated in two different facilities

    ☐ If so, approximately how far away from each other? _____________________

11. Do you have any children: ________ If so, how many? _________

Questions:

1. Can you tell me a little bit about yourself and your partner?
    a. How long have you been together and/or married?
    b. What are some things you and your partner like(ed) to do together?
2. Tell me about when your spouse began to need some assistance?
    a. Were you your partners main caregiver?
    b. How long were you providing care to your partner before she/he was admitted to a care home?
    c. Was there a specific event that triggered moving your partner to a care home?

3. What was the primary reason you moved into LTC/AL?
    a. What led you to move with your partner?
4. If living in two separate facilities: How did this arrangement come about?
    a. Were there concerns about costs of care or finances that led to you being separated from your partner?
5. Can you tell me about the emotional impact of being separated from your partner?
    a. What is something you miss most about living with them?
6. Have you noticed any change to your physical health since being separated from your partner?
7. How often are you able to see your partner?
    a. Are there any challenges in doing so?
    b. Would you like to visit more?
8. Can you describe a typical visit with your partner?
    a. What do you do with them?
    b. When you visit, where do you like to be with your partner? (e.g., Their room, common areas/seating areas) And Why?
9. When you visit your partner, what you do like to do together?
    a. Have meals, coffee, listen to music, or for walks etc.?
    b. What would you like to do with them that you are not able to? (e.g., have meals, intimacy, activities)
10. How has your relationship with your partner changed since moving to a care home?
    a. Have these changes in your marriage changed how you think about yourself as a wife/husband?
11. Have you noticed a change in your partners health since being separated?
    a. Faster cognitive decline?
    b. Has their physical health changed?
12. When you leave your partner after visiting, how do you feel?
    a. Sad, anxious, etc.?
    b. Do you miss them?
    c. Do you worry about them?
13. What does it mean to you to be able to maintain your relationship with your partner?
14. How do you feel about the staff at the care home where your spouse is living?
    a. Are you comfortable with them?
    b. Do you feel that you can ask questions about your partners care, or voice your concerns?
    c. Do you feel that they provide you with support?
        i. Emotional support?
15. What do you think would help you better maintain your relationship with your spouse?
    a. Such as transportation? Staying in the same facility? Same room? Eating together?
    b. What are your recommendations?
16. That completes the interview. Is there anything we haven’t talked about that you would like to share?
    a. Things you think I missed?
    b. Something you think is important to add or talk about?

Secondary Questions (if time permits):

1. What are the benefits of moving into a care home for you?
    a. Do you have more time for yourself?
    b. Do you feel a change in your mood and/or well-being? (e.g., stress levels, anxiety, happiness etc.)
2. What do you think has been the most beneficial thing about moving into a care home for your partner?
    a. Do you feel a change in their mood and/or well-being? (e.g., stress levels, anxiety, happiness etc.)
    b. Do you think your partner is getting the care they need?
3. If you were to tell a friend in a similar situation as yours, what would you say?
4. Does your partner have a roommate?
    a. If yes:
        i. Do you get along with their roommate?
        ii. Do you feel that your partner having a roommate make it more difficult to have privacy?
        iii. How has your partner having a roommate interfered with how you use your partners room when you visit?

Thank you so much for your participation in this study, I really appreciate your time and openness with me.

Appendix C.

Interview Guide: Persons with Dementia

Hi, my name is _____________ is it alright if I ask you a few questions today about your relationship with __________ (partners name)? Your answers will be part of a study that aims to share the experiences of couples who can't live together in LTC. Your expertise and answers will help other couples in the future maintain their relationship with their partner.

Read/Explain informed consent form again. Assure confidentiality.

<u>Questions:</u>

1. I know your partner ______, can you tell me a little bit about your life together/relationship?
    a. How long have you been together and/or married?
    b. How did you meet?
    c. What are some things you like(ed) to do together? (e.g., travel, go to restaurants, watch movies, go to the theatre, bike riding, walks, etc.)
        i. Do you have a favourite memory or story?
    d. Do you have any children?
2. When ______ (partners name) comes to visit, what do you like to do together?
    a. If there is something in specific their partner mentioned ask them about that activity
    b. Other prompts: Have coffee, listen to music, have lunch? Go for a walk?
3. When ________ (partners name) leaves, how do you feel?
    a. Do you miss them?
    b. Do you feel sad?
    c. Do you worry about them?
4. Do you think your relationship with _____ (partners name) has changed since moving here?
    a. Do you still feel close to them_______ (partners name)?
    b. Do you feel like you can do most of the same things as before you moved here?
    c. Do you wish you can see _______ (partners name) more?
5. What do you miss most about not living with __________ (partners name)?
6. Do you think the care staff understand your relationship with _________ (partners name)?
    a. Do you think they understand how important _________(partners name) is to you?
    b. Do they give you privacy when _________ (partners name) comes to visit?
    c. Do you think the staff like having _________ (partners name) around?
7. Do you have a roommate?
    a. If yes:
        i. Do you like your roommate?

    ii. Does your roommate and _________ (partners name) get along?
    iii. Is your roommate around when _________ (partners name) comes to visit in your room?

8. What do you think would help maintain your relationship with _________ (partners name)?
    a. Having them visit more often?
    b. Being able to live together in the same room?
    c. Having more time together?
    d. More privacy?
    e. More meals together?
9. That completes the interview. Is there anything we haven't talked about that you would like to share?
    c. Things you think I missed?
    d. Something you think is important to add or talk about?

Thank you so much for your participation in this study, I really appreciate your time and openness with me.

Appendix D.

Focus Group Interview Guide and Questions

Demographic Details Questionnaire

Please answer the following questions in the spaces provided, circle or tick the most appropriate options.

1. Place of work: _________________________
2. Gender *(Optional)*: ☐ Male ☐ Female ☐ Other: ________
3. Age: _________
4. What is your professional background?
   ☐ Nurse (RN)
   ☐ Nurse (LPN)
   ☐ Care aide/care support worker
   ☐ Other: (please describe) _____________________________________

5. How many years of experience have you had in this current job?
   ☐ <1 Year ☐ 1-2 Years
   ☐ 2-5 Years ☐ 5-10 Years
   ☐ >10 Years

6. Are you aware of B.C.'s provincial policy that mandates assisted living and residential care facilities to accommodate married couples with differing care needs?
   ☐ Yes ☐ No

Thank you for taking the time to complete this questionnaire

Discussion Guide

Opening Remarks and Introductions:

<u>Welcome:</u>

Hello everyone! Thank you all for coming and for volunteering to take part in this focus group.

<u>Introduction of moderator and assistant/notetaker:</u>

Have each introduce themselves, state their names, their role, and a little background about themselves (e.g., education, research interests). (e.g., my role as moderator will be to facilitate our discussion today, my role as an assistant/notetaker is to observe and take notes).

Purpose:

The purpose of this session is for you to share your experiences and thoughts about the accommodation of married couples in LTC settings. Specifically, we want to understand some of the means by which you provide space for spousal relationships, some of the challenges you may face in doing so, and the social and physical environmental features of LTC that may impact married couples' abilities to maintain their relationship.

The information learned from this focus group will be used to develop interventions, education in care practices, and policy. The session will take no more than 60min and will be recorded. The recording will be used to ensure that today's discussion is captured in its entirety and that our notes are correct. No one outside of the project team will hear this recording.

Guidelines:

A few things to keep in mind for our session today.

- *There are no right or wrong answers:* We want to hear a variety of opinions. Everyone's perspectives and experiences are valuable and important to this study. Even if your views differ from those of the rest of the group, we hope you will be open and honest. We don't expect you to agree with everyone, but we expect you to listen with respect when others express their opinions.
- *Everything said in this session is confidential:* This is a safe space, and we want everyone to feel comfortable sharing their perspectives and experiences. We ask that you refrain from speaking about other's comments outside of this session. This session will be recorded; however, your answers will remain anonymous, and your names will not be included in the final report. We are all on a first-name basis only.
- *We want to hear from everyone:* Out of respect for one another, we ask that only one person speaks at a time. I may call on you if you haven't talked in a while. If there are any questions you do not wish to answer, you do not have to do so. You also can choose not to participate and withdraw from the study at any time.

Lastly, we ask that you keep your cellphones away and on silent for the duration of this session. If you need to respond to a call or text, we ask you to please leave the room, and rejoin as quickly as possible.

Questions:

1. Opening/Ice Breaker Question:
   Pease share with us your name and one place you would like to travel to and why?
2. Introductory Question:
   When you think of residents' marital relationships, what comes to mind?
3. Transition Question:
   How would you describe marital relationships in LTC?
4. Content Questions:
   a. Content 1: What are your thoughts about residents' spouses visiting?
      i. What are the effects of spouses' visits on the residents? (Well-being, mood, functioning)
      ii. Are there things that staff can do to ensure they have a meaningful visit with their spouse?
   b. Content 2: Do you notice a change in behavior or demeanor in married residents with dementia when their spouse leaves?
      i. Do you think they feel sad, anxious, or angry?
      ii. Presence of responsive behaviors? (Before vs. after?)
      iii. Do spouses have difficulty leaving? Do you need to re-direct residents so their spouse can leave?
      iv. Do you have any examples? /Is there a specific couple/situation you are thinking of?
   c. Content 3: What are some of the challenges to create space for couples and opportunities for them to maintain/continue their relationship?
      i. Is there suitable and enough spaces in the care home where couples can have privacy during visitations?
      ii. Do you have enough information about a couple's life history to support their relationship, such as allowing them to continue some of their routines before they relocated to LTC?
      iii. Do you have any examples? /Is there a specific couple/situation you are thinking of?
   d. Content 4: In what ways can care homes be more supportive for married couples?
      i. Do you think having couples live together in the care home would be helpful to support the relationship?
      ii. Are there policies that could be changed to allow for more opportunities for couples to spend more meaningful time together? (e.g., are couples allowed to have meals together?)
      iii. Relevant education for staff?
      iv. Providing transportation for spouses to visit each other between facilities easier?
5. Is there anything anyone else would like to talk about and share that wasn't mentioned?

Closing remarks:

Thank you all so much for taking the time to participate! Your insights and comments are extremely valuable to this research.

Appendix E.

Informed Consent: Focus Group Participation

‘Till Long-Term Care Do We Part’: Exploring the Impacts of Separating Married Couples on Couplehood and Well-being

Principle Investigator: Lindsay Grasso

Investigator Department: Department of Gerontology

What is the purpose of this study?

This study aims to critically examine the institutional practice of separating married couples in long term care (LTC) settings in British Columbia when one spouse lives with dementia and requires different care and support. Specifically, couples' abilities and challenges to maintain the quality of their relationship in LTC settings and investigate how separation influences the health and well-being of both spouses'.

What will you be required to do?

You will be asked to participate in an approximately 1–2-hour focus group session with 5-7 fellow LTC care staff (nurses and personal support workers). A moderator will ask you several questions while facilitating the discussion. The focus group will consist of six open-ended questions that will cover the care practices, policies, staff perspectives about the impacts of separation on persons with dementia, and environmental features of LTC settings that challenge couples' abilities to maintain their relationship. Trained research assistants will conduct the focus group session. Focus group sessions will be completed at either the LTC home's (one session per site) considering convenience or at a nearby community setting. The session will be audio-recorded, and a notetaker will be present.

What are the risks of this study?

There are no foreseeable risks to you in participating in this study. All information collected for this study will be kept confidential. It is requested that you do not repeat any information shared during the focus group session, and that you recognize that we have no control over what other session participants do with the information once the session is completed. Permission to conduct this study has been obtained from the LTC home in which you are employed, therefore there is no risk to your position or employment in taking part of this study.

What are the benefits of this study?

Knowledge gained through this study will be used to encourage further research and help to improve current policies and establish supportive interventions and care practices that promote the continuity of spousal relationships in LTC settings. If you agree to participate in the project, you will get a $25 honorarium for your time. Light refreshments are also provided at the session.

Do I have to take part in this study?

Participation in this study is entirely voluntary and you are allowed to withdraw yourself at any point in time. You can choose not to answer any questions in the session that you are uncomfortable with. If you opt to leave the study after data collection, the research team may keep and utilize the data that has already been gathered in reports for this study. Withdrawal or refusal to patriciate will not adversely affect your position or employment at the residential care home in which you are representing and that is also participating in this study.

Organization permission:

Permission to conduct this research study from the LTC home in which you are employed has been obtained.

Will taking part in this research be kept confidential?

All the data collected as part of this study will be confidential. Your name, identifying characteristics and any personal information collected (e.g., place of work) will be kept confidential and safeguarded to the fullest extent of the law. Publications, reports, or presentations based on this study will not include any real names of participants. Full confidentially cannot be maintained in a group setting. We encourage participants not to discuss the content of the focus group to people outside the groups; however, we cannot control what participants do with the information discussed. Participants will not be identified by name in any reports of the completed study.

All the data collected will be anonymized, which involves removing any names, organizations, or information that would identify you or another person personally, mentioned will be removed. All materials and data will be kept in a secure location and will be password protected. You have 60 days after your focus group session to notify the research team if you do not want your responses published. Once published, information provided will no longer be able to be withdrawn.

What will happen to the results of this research?

N/A

Who can I contact if I have questions about this research during my participation?

If you have any concerns about your rights as a research participant and/or your experiences while participating in this study, you can contact Lindsay Grasso at xxxxxxx@sfu.ca. You may also contact Dr. Jeffrey Toward, Director, Office of Research Ethics xxxxxx@sfu.ca or xxx-xxx-xxxx.

Future Contact:

Researchers in the future may wish to contact you for participation. Do you consent to be contacted in the future? Do you agree to future contact? ☐ Yes ☐ No

Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason and without any negative impact on your [examples should be relevant to the participant and could include references to employment, class standing, access to further services from the community centre, day care, etc.].

- Your signature below indicates that you have received a copy of this consent form for your own records.
- Your signature indicates that you consent to participate in this study.
- You do not waive any of your legal rights by participating in this study.

By signing this form, I ensure that I have read the above in full and agree to participate:

______________________	______________________	________________
Participant Signature	Printed Name	Date

If you have any questions about this research study or if you wish to obtain copies of the results upon the study's completion you can contact:

Lindsay Grasso
MA Candidate
Department of Gerontology
Simon Fraser University
2800-515 West Hastings Street Vancouver, BC V6B 5K3
xxxxxxxx@sfu.ca

Appendix F.

Informed Consent: Spousal Caregivers

‘Till Long-Term Care Do We Part’: Exploring the Impacts of Separating Married Couples on Couplehood and Well-being

Principle Investigator: Lindsay Grasso

Investigator Department: Department of Gerontology

What is the purpose of this study?

This study aims to critically examine the institutional practice of separating married couples in long term care (LTC) settings in British Columbia when one spouse lives with dementia and requires different care and support. Specifically, couples' abilities and challenges to maintain the quality of their relationship in LTC settings and investigate how separation influences the health and well-being of both spouses'.

What will you be required to do?

You will be asked to take part in an interview lasting approximately 60 to 90 minutes. Interviews will take place at your convenience and will be coordinated around the care home's routines (e.g., meals and activities), caregiving duties, and personal appointments. A researcher will conduct the interview, which will take place in a designated private area (e.g., conference rooms, family visiting rooms, etc.) or in your bedroom if you prefer. The interview will address how separation from your partner has impacted your relationship, the means by which you maintain your relationship, the impact of separation on your overall health and well-being, and how the LTC environment has impacted your abilities to maintain your desired relationship quality. The interview will be audio recorded.

What are the risks of this study?

There are no foreseeable risks to you in participating in this study. This is a ‘minimal risk’ study in which you are sharing your thoughts and experiences. Permission to conduct this study has been obtained from the home in which you reside, therefore there is no risk to your housing, care, or that of your partner because of your participation. Participation will require a marginal time commitment, and we do not believe anything in this study will harm you or be damaging to your health. Some of the questions we ask could make you uncomfortable, and you can choose not to answer those that make you feel uncomfortable. If you have any concerns, please inform a member of the study team. All information collected during this study will be kept confidential.

What are the benefits of this study?

Knowledge gained through this study will be used to encourage further research and help to improve current policies and establish supportive interventions and care practices that promote the continuity of spousal relationships in LTC settings. The interview is aimed to allow you to share and reflect on your experiences, which may directly contribute to the improvement of the lives of future couples in this situation and the development of initiatives that can assist you today.

Do I have to take part in this study?

Participation in this study is entirely voluntary and you are allowed to withdraw yourself at any point in time. You can choose not to answer any questions during the interview that you are uncomfortable with. If you opt to leave the study after data collection, the research team may keep and utilize the data that has already been gathered in reports for this study. Withdrawal or refusal to patriciate will not adversely affect your housing, care, or that of your partners.

Organization permission:

Permission to conduct this research study from the residential care home in which you reside has been obtained.

Will taking part in this research be kept confidential?

All the data collected as part of this study will be confidential. Your name, identifying characteristics and any personal information collected (e.g., place of work) will be kept confidential and safeguarded to the fullest extent of the law. Publications, reports, or presentations based on this study will not include any real names of participants. Participants will not be identified by name in any reports of the completed study.

All the data collected will be anonymized, which involves removing any names, organizations, or information that would identify you or another person personally, mentioned will be removed. All materials and data will be kept in a secure location and will be password protected. You have 60 days after your focus group session to notify the research team if you do not want your responses published. Once published, information provided will no longer be able to be withdrawn.

What will happen to the results of this research?

N/A

Who can I contact if I have questions about this research during my participation?

If you have any concerns about your rights as a research participant and/or your experiences while participating in this study, you can contact Lindsay Grasso at xxxxxxx@sfu.ca. You may also contact Dr. Jeffrey Toward, Director, Office of Research Ethics xxxxxx@sfu.ca or xxx-xxx-xxxx.

Future Contact:

Researchers in the future may wish to contact you for participation. Do you consent to be contacted in the future? Do you agree to future contact? ☐ Yes ☐ No

Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason and without any negative impact on your [examples should be relevant to the participant and could include references to employment, class standing, access to further services from the community centre, day care, etc.].

- Your signature below indicates that you have received a copy of this consent form for your own records.
- Your signature indicates that you consent to participate in this study.
- You do not waive any of your legal rights by participating in this study.

By signing this form, I ensure that I have read the above in full and agree to participate:

Participant Signature	Printed Name	Date

Audio Recording

☐ Yes, I may be audio- recorded

If you have any questions about this research study or if you wish to obtain copies of the results upon the study's completion you can contact:

Lindsay Grasso
MA Candidate
Department of Gerontology
Simon Fraser University
2800-515 West Hastings Street Vancouver, BC V6B 5K3
xxxxxxxx@sfu.ca

Appendix G.

Informed Consent: Persons with Dementia

This form will be read out-load by the interviewer before the interview to the dementia participant to verify that the study's details are understood, and that consent is acquired.

‘Till Long-Term Care Do We Part’: Exploring the Impacts of Separating Married Couples on Couplehood and Well-being

Principle Investigator: Lindsay Grasso

Investigator Department: Department of Gerontology

What is the purpose of this study?

This study aims to examine the practice of separating married couples in long term care (LTC) settings in British Columbia when one spouse lives with dementia. Specifically, couples' abilities and challenges to maintain the quality of their relationship and investigate how separation effects the health and well-being of both partners'.

What will you be required to do?

You will be asked to take part in an interview lasting approximately 60 to 90 minutes. Interviews will take place at your convenience and will be coordinated around the care home's routines (e.g., meals and activities), and personal appointments. A researcher will conduct the interview, which will take place in a designated private area (e.g., conference rooms, family visiting rooms, etc.) or in your bedroom if you prefer. The interview will address how separation from your partner has impacted your relationship, how you maintain your relationship, the impact of separation on your overall health and well-being, and how the LTC environment has impacted your abilities to maintain your desired relationship quality. The interview will be audio and video recorded with your consent.

What are the risks of this study?

There are no foreseeable risks to you in participating in this study. This is a ‘minimal risk’ study in which you are sharing your thoughts and experiences. Permission to conduct this study has been obtained from the home in which you reside, therefore there is no risk to your housing, care, or that of your partner because of your participation. Participation will require a marginal time commitment, and we do not believe anything in this study will harm you or be damaging to your health. Some of the questions we ask could make you uncomfortable, and you can choose not to answer those that make you feel uncomfortable. If you have any concerns, please inform a member of the study team. All information collected during this study will be kept confidential.

What are the benefits of this study?

Knowledge gained through this study will be used to encourage further research and help to improve current policies and establish supportive interventions and care practices that promote the preservation of spousal relationships in LTC settings. The interview is aimed to allow you to share your experiences, which may directly contribute to the improvement of the lives of future couples in this situation and the development of initiatives that can assist you today.

Do I have to take part in this study?

Participation in this study is entirely voluntary and you are allowed to withdraw yourself at any point in time. You can choose not to answer any questions during the interview that you are uncomfortable with. If you opt to leave the study after data collection, the research team may keep and utilize the data that has already been gathered in reports for this study. Withdrawal or refusal to patriciate will not adversely affect your housing, care, or that of your partners.

Organization permission:

Permission to conduct this research study from the residential care home in which you reside has been obtained.

Will taking part in this research be kept confidential?

All the data collected as part of this study will be confidential. Your name, identifying characteristics and any personal information collected (e.g., place of work) will be kept confidential and safeguarded to the fullest extent of the law. Publications, reports, or presentations based on this study will not include any real names of participants. Participants will not be identified by name in any reports of the completed study.

All the data collected will be anonymized, which involves removing any names, organizations, or information that would identify you or another person personally, mentioned will be removed. All materials and data will be kept in a secure location and will be password protected. You have 60 days after your focus group session to notify the research team if you do not want your responses published. Once published, information provided will no longer be able to be withdrawn.

What will happen to the results of this research?

N/A

Who can I contact if I have questions about this research during my participation?

If you have any concerns about your rights as a research participant and/or your experiences while participating in this study, you can contact Lindsay Grasso at xxxxxxx@sfu.ca. You may also contact Dr. Jeffrey Toward, Director, Office of Research Ethics xxxxxx@sfu.ca or xxx-xxx-xxxx.

Future Contact:

Researchers in the future may wish to contact you for participation. Do you consent to be contacted in the future? Do you agree to future contact? ☐ Yes ☐ No

Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason and without any negative impact on your [examples should be relevant to the participant and could include references to employment, class standing, access to further services from the community centre, day care, etc.].

- Your signature below indicates that you have received a copy of this consent form for your own records.
- Your signature indicates that you consent to participate in this study.
- You do not waive any of your legal rights by participating in this study.

By signing this form, I ensure that I have read the above in full and agree to participate:

______________________	______________________	________________
Participant Signature	Printed Name	Date
______________________	______________________	________________
Substitute Decision Maker	Printed Name	Date

Audio and Video Recording

☐ Yes, I may be video recorded

☐ Yes, I may be audio recorded

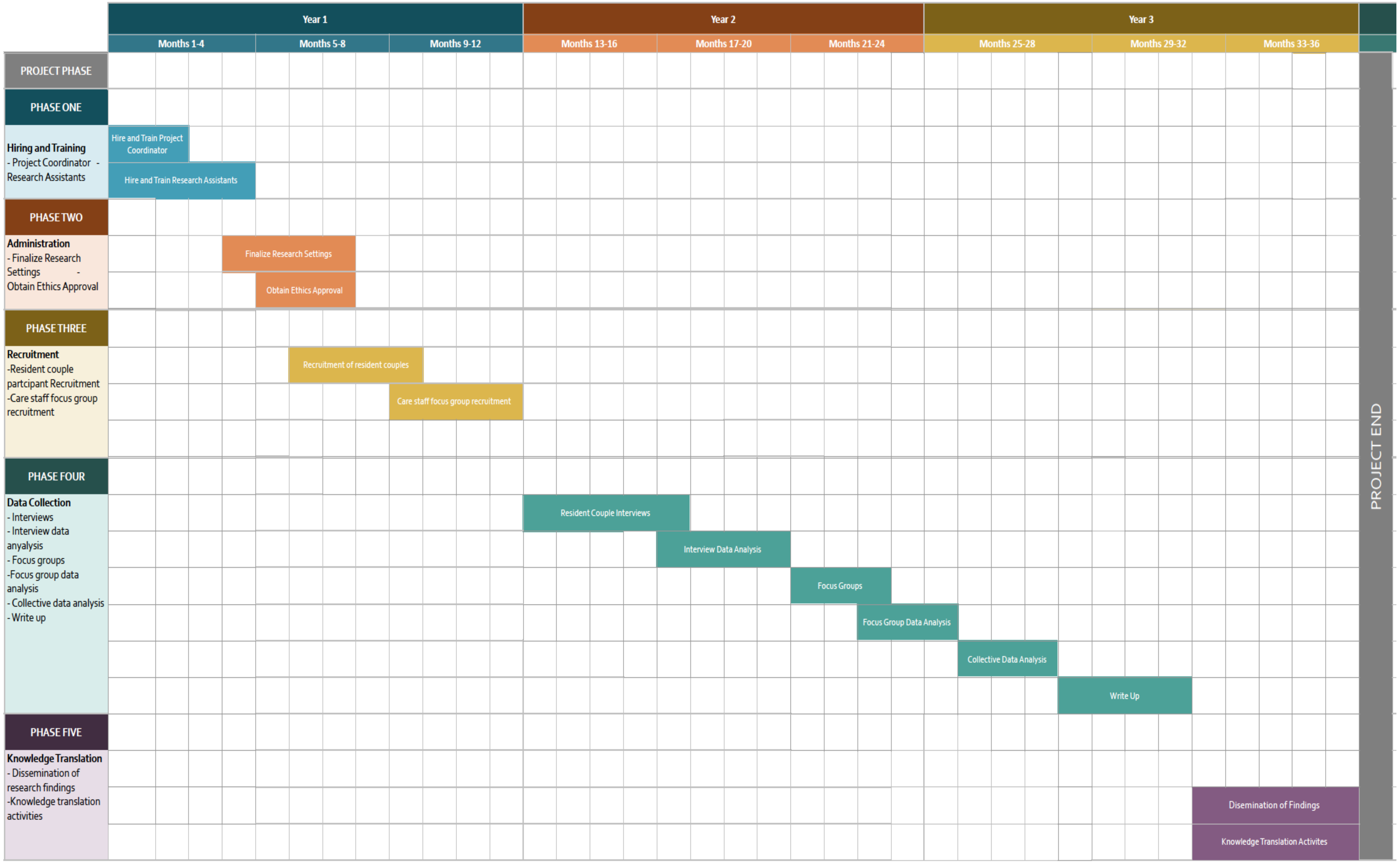
If you have any questions about this research study or if you wish to obtain copies of the results upon the study's completion you can contact:

Lindsay Grasso
MA Candidate
Department of Gerontology
Simon Fraser University
2800-515 West Hastings Street Vancouver, BC V6B 5K3
xxxxxxxx@sfu.ca

Appendix H.

Project Timeline

PROJECT TIMELINE



Appendix I.

Project Budget

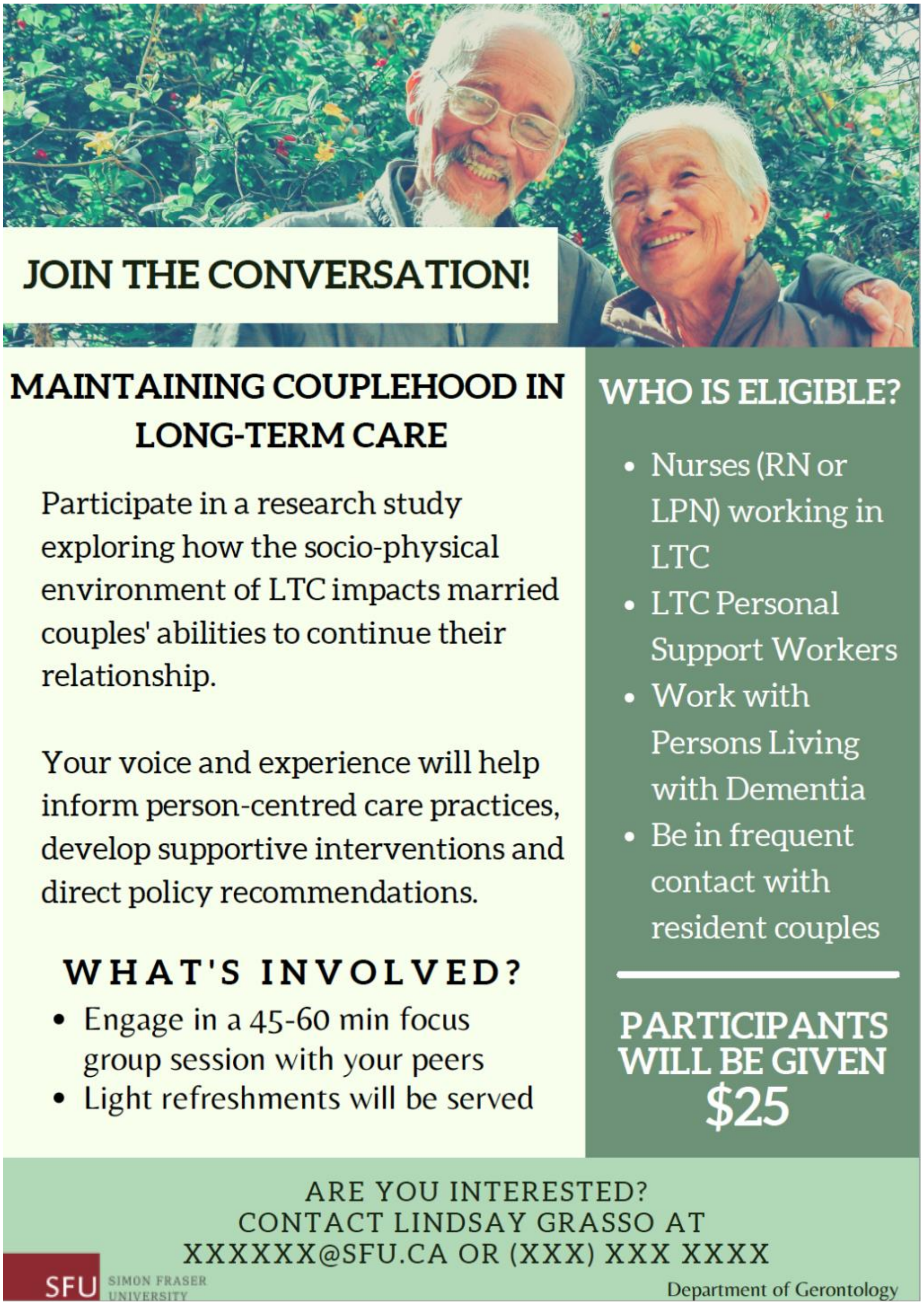
Period of Support Requested: 3 Years 0 Months

Category	**Amount (In thousands)**
Research Staff	
1 Project Coordinator: Responsible for coordinating the overall research project, performing administrative tasks, hiring, and managing research assistants, overseeing participant recruitment, managing, and performing participant interviews and focus groups, data analysis, arranging and preparing scholarly journals and conference presentations. $29.95/hour + 12% benefits @ 20hrs/week x 50 weeks/yr = $29,950/yr x 3yrs = $100,632	$100, 632
2 Research Assistants: They are hired at the beginning of the project. Under the supervision of the Project Coordinator, they are graduate students who will assist in recruiting participants and conducting the participant interviews and focus groups, transcription, and assistance with data analysis. They will also assist in the preparation of workshop materials and written reports, and knowledge translation. $22.80/hr + 12% benefits @ 20 hrs/wk x 50 wks/yr = $22,800/yr x 3yrs = $68,400 x2 = $153,216	$153,216
Consumables	
Travel for Data Collection: Bus pass $208 per month x3 (Each research Staff) @ $2,496 per 1yr or the equivalent for gas ($208 per month) x3yrs = 22,464	$22,464
Miscellaneous Costs: Office supplies, marketing/advertisements, printing/copies, $650/yr x3yrs = 1,950	$1,950
Non-Consumables	
Laptops: Touchscreen Laptop - Silver (Intel Celeron N4020, 4GB RAM, 64GB eMMC, Intel UHD, Windows 10 in S Mode): $399.99 +12% taxes +$1.60 eco fee x 2 = $897.77	$897.57
Audio Recorder: Sony 4GB Digital Voice Recorder with Built-in USB (ICDUX570BLK) - Black: $119.99 +12% taxes x2 + 0.70 eco fee = $270.64	$270.64
Flash Drive: Philips Vivid 64GB USB 3.0 Flash Drive - 3 Pack: $39.99 +12% taxes = $44.79	$44.79

Category	Amount (In thousands)
Microsoft Office: Microsoft Office Home & Student 2019 (PC) - English $169.99 +12% taxes x2 = 190.39	$380.77
Nvivo Subscription with Transcription service	$1,031.89
Knowledge Translation	
Presentation/Workshop Costs: Room rental: $100/4 hours x 4 sessions = $400 Info packages: 50 packages = $700 Refreshments for approx. 50 people (tax incl): Assorted sandwich patter $164.5 + coffee $89 + dessert platter $77.50 + veggie/fruit platter $60 = $391	$1,491
Conference Presentations: Travel costs for project coordinator to attend two conferences (CAG & CGNA) tax incl Conference(s) registration: CAG $395 + CGNA $590 = $985 Flights: (Canadian destination) $800 x 2 destinations = 1,600 Hotels: $200 incl taxes/night x 8 nights (4 nights per conference) = $1,600 Per diem: $60/day x 8 days (4 days per conference) = $480	$4,665
Journal Publication Preparation, Fees, etc. $2000 x 2 journals	$4,000
Other	
Focus Group Participant Honoria: $25 x approx. 40 participants	$1,000
Focus group Refreshments for approx. 8 people: Assorted sandwich platter $35.63 + coffee $44.99 + assorted pastry platter $14.40 = $95.02 per session x approx. 6 sessions = $570.12	$570.12
Entire Amount Requested	$292,468.40

Appendix J.

Recruitment Flyer



JOIN THE CONVERSATION!

MAINTAINING COUPLEHOOD IN LONG-TERM CARE

Participate in a research study exploring how the socio-physical environment of LTC impacts married couples' abilities to continue their relationship.

Your voice and experience will help inform person-centred care practices, develop supportive interventions and direct policy recommendations.

WHAT'S INVOLVED?

- Engage in a 45-60 min focus group session with your peers
- Light refreshments will be served

WHO IS ELIGIBLE?

- Nurses (RN or LPN) working in LTC
- LTC Personal Support Workers
- Work with Persons Living with Dementia
- Be in frequent contact with resident couples

PARTICIPANTS WILL BE GIVEN $25

ARE YOU INTERESTED?
CONTACT LINDSAY GRASSO AT
XXXXXX@SFU.CA OR (XXX) XXX XXXX

SFU SIMON FRASER UNIVERSITY

Department of Gerontology

Note: Image from Canva

Appendix K.

CIHR Project Grant: Fall 2020 and Spring 2021 Guidelines

Description: The attached PDF document details the guidelines for the CIHR Project Grant. The document lists the requirements for the grant application, which was used as a template for completing Chapter 5 of this project.

Filename: Project Grant- Fall 2020 and Spring 2021 CIHR Guidelines.pdf