

THE LIVED EXPERIENCE OF SPOUSAL TRANSITION WITHIN DEMENTIA AND
RELOCATION TO LONG TERM CARE

By

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A Thesis

Submitted to the Faculty of Graduate Studies
in partial fulfillment of the requirements
for the degree of

MASTER OF PSYCHIATRIC NURSING

Faculty of Health Studies
University of Brandon
Brandon, Manitoba

January 7, 2016

ACKNOWLEDGMENTS

The fulfillment of this thesis has been possible with the support and assistance of several people.

I dedicate this work to my children, Matt and Sara, and in memory of my Mom and Dad.

A special thank you to the participants who welcomed me into their homes and shared their experiences. The knowledge and wisdom gained will make a difference in the lives of many.

Thank you to:

my advisor, Dr. Frances Racher, for her time, knowledge, and commitment to my learning and nursing practice;

my committee members, Cathy Foster and Dr. Ron Richert for the generosity of sharing their expertise and wisdom;

my family and friends for their support, care, and understanding;

my work colleagues, as they encouraged my efforts;

and my fellow classmates, while we learned together.

This research was supported by an Alzheimer Society of Manitoba fellowship award.

ABSTRACT

The purpose of this project was to gain understanding of the transition experience of older couples when one of the partners has been diagnosed with dementia, the couple can no longer continue their life together in their own home, and the partner with dementia has relocated to long term care. During this phenomenological study, spousal caregivers were interviewed and asked to describe the experiences of their partners' relocation to long term care. In the later stages of dementia, the perspective of the spousal caregiver is essential for understanding the related transitions. The caregivers were asked to share their experience, their perspective of their partners experience and their experience as couple units. Spousal caregivers described their lives leading up to the need for relocation, managing relocation, and adapting to life after relocation. Caregivers reported individual, yet interdependent challenges that they experienced as well as their strengths and abilities to cope during the transitions. The findings from this study will contribute to the current literature informing health care practice and policy in supporting couples' and their choices throughout the trajectory of living with dementia. The application of this knowledge within multiagency and interdisciplinary fields will better serve each of the partners within the couple, and of the couple as the unit of care.

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Chapter 1 - Introduction

Dementia researchers will endeavor to discover the causes and cures of Alzheimer's disease. Medical science is making advances through neurological assessment and pharmaceutical treatment of dementia. Improved awareness of disease symptoms as well as supportive services and interventions may lead to prevention of physical, social, and relational complications. In the midst of these aspects exists the need and ability to live with the disease. Illness requires care and caregiving often begins with spousal partners. This research study provided an opportunity to gain a better understanding of the experience of the couple through the perspective of the caregiving partner. Caregiver experience and knowledge on transition from living together as a couple to remaining a couple while one of the partners has relocated to long term care (LTC) due to the trajectory of dementia, may assist in the development of a health care system which is better able to support and guide spousal couples.

By 2026, the proportion of Manitobans 65 years of age and older will increase from 14.1% to 19.9% of the Province's population (Centre on Aging, 2010). As the Canadian population ages, dementia-related health issues will increase accordingly and will require the health care system to adapt to meet the related health care needs (Canadian Institute for Health Information, 2011). Demands upon family, friends, and society will increase as well. Knowledge of the experiences of older couples living with dementia will be important in meeting the needs of the spousal caregivers, the partners with dementia, and the couple units.

In the comprehensive study, *Rising Tide: The Impact of Dementia on Canadian Society*, commissioned by the Alzheimer Society of Canada (2010) the important role played by informal caregivers, including marital partners, is recognized. Conversation with spousal caregivers provides increased understanding of the experiences of couples when one of the partners has

been diagnosed with dementia (Hellstrom, Nolan, & Lundh, 2005; McGovern, 2011; Molyneaux, Butchard, Simpson, & Murray, 2012). The ability of the caregiving spouses to embrace the change in their partners with dementia is crucial to the maintenance of wellbeing for the individuals and for the couple unit.

When health care service providers engage with elderly couples as the unit of care, they will recognize that the spouses do not stop being a couple when one of the partners relocates to LTC. When health care service providers understand the concept of couplehood they adapt services to better support the couple's ongoing relationship and provide a valuable contribution to the quality of life for the spousal caregiver, the partner with dementia, and the couple unit as they live within this transition.

The purpose of this project was to gain better understanding of the transition experience of older couples when one of the partners has been diagnosed with dementia and the couple has reached a point where they can no longer continue their life together in their own home. At this point, the partner diagnosed with dementia would relocate to a LTC facility. The spousal caregivers were considered to be the experts regarding the needs of the partners with dementia, their own needs as caregivers, and the needs of the couple. The spousal caregivers shared their experiences of the trajectory of dementia throughout the transitions leading up to relocation, managing the relocation, and adapting to life apart following relocation to long term care (LTC).

The methodological principles of hermeneutic phenomenology (Creswell, 2013; van Manen, 1997) were used as the basis for analysis of the data which were gathered through dialogue that was recorded and transcribed. In addition, field notes were kept of the contexts of the interviews. Insight into the lived experience of transition through the trajectory of dementia was gathered through participants' descriptions of their experiences as they have lived through

specific events. Reflection on the experiences, as described by the spousal caregiver, were used to guide the identification of themes. The phenomenological process of van Manen (1997, 2014) was used to analyze and portray evolving themes through the interpretive tasks of organizing the dialogue from the interviews. This human science approach provided the opportunity to reflectively seek to understand the experiences of the couples through the transition. The research questions were designed to gather understanding of the lived experience of the couple through the perspective of the spousal caregiver.

Research Questions

Spousal caregivers were interviewed and asked to describe their experiences of the transition to LTC. Since the partners with dementia were not able to give their descriptions, the spousal caregivers were asked to give their perspective of the experiences of their partners. In addition, the spousal caregivers were asked to describe the experience from a couple's perspective.

Primary research question.

What is the experience of the couple when the partner, who has been diagnosed with dementia, must relocate to a long term care facility?

Related questions.

What is the experience of transition to long term care like for the spouse who is the caregiver?

From the perspective of the caregiving spouse, what was the transition experience like for the partner who relocated?

From the perspective of the caregiving spouse, what was the transition experience like for the spouse and the partner, as a married couple?

Chapter 2 – Literature Review

Qualitative research to explore dementia originated with separate foci on the experiences of the caregivers of the person with dementia (Kraijo, Brouwer, de Leeuw, Schrijvers, & van Exel, 2012) and the experiences of the persons diagnosed with dementia (Robinson, Giorgi, & Ekman, 2012). More recently the focus has shifted to include the communication patterns between the caregiver and the person diagnosed with dementia (Braun, Scholz, Bailey, Perren, & Hornung, & 2009). The spousal couple's interdependence within the lived experience of dementia is the target of increased awareness and understanding of ways that their individual and couple needs are met (Molyneaux, Butchard, Simpson, & Murray, 2012). While some studies have been undertaken to understand the experiences of the couple living with dementia (McGovern, 2011), efforts to understand their experiences of the transition to LTC is quite limited (Slaughter & Bankes, 2007). Through an extensive review of the literature related to dementia and caregiving, the need for further understanding of the lived experiences of couples living with later-stage dementia became apparent. In particular, few studies have been conducted to understand the experiences of the couple during the trajectory of dementia, when marital partners transition from living together to living apart.

This literature was gathered through a search of electronic databases including Academic Search Premier, CINAHL, Health Source, PsychInfo, and SocIndex. The following search words were used individually in a standard search and in various combinations through an advanced search: Alzheimer's disease, dementia, mild cognitive impairment, caregiving, coping, couples, and dyads. Additional references were gathered from the reference lists of the original articles, from colleagues, and from other articles gathered from previous exploration of related topic areas. This review will be used to provide a synthesis of literature that delves into

evidence-based practice geared toward understanding and assisting older couples within which one of the partners has been diagnosed with dementia. This literature review will include discussions of the trajectory of dementia; the experience of the disease from the perspective of the person diagnosed with dementia, family caregivers, and spousal caregivers; and spousal transition.

A review of the trajectory of dementia is an important starting point within the exploration of approaches to care. Appropriate care is related to the needs and abilities of all involved in this disease process. A person-centered approach, focused on the perspective of the caregiver, has given way to exploration of a relationship-centered focus throughout the current literature. Caregiver relationships are distinguished separately as family and spousal roles and responsibilities. The phenomenon of transition is explored as experienced in the relationship of caregiving for a family member who has been diagnosed with dementia. The gap in the literature is indicative of the need for a research study exploring the experience of the spousal transition of living with dementia and relocating to LTC.

The Trajectory of Dementia

Dementia is a chronic and progressive disease caused by various illnesses of the brain; and is the most common syndrome that affects memory, thinking, behavior, and the ability to perform everyday activities (Alzheimer Society of Canada, 2010; American Psychiatric Association, 2000; World Alzheimer Report, 2011). Dementia (American Psychiatric Association, 2000) is a term more commonly known to the public and used by organizations, such as the Alzheimer's Society, rather than the more recent term of major neurocognitive disorder (American Psychiatric Association, 2013). Dementia is seriously disabling for those individuals who have it and is often devastating for their caregivers and families (Blieszner,

Roberto, Wilcox, Barham, & Winston, 2007). Irreversible and progressive dementias include Alzheimer's disease, vascular dementia, Lewy body dementia, and frontotemporal dementia (American Psychiatric Association, 2013). These four types are considered to be Alzheimer's type dementias (Sherrell & Iris, 2005) and are the focus of this study. Throughout this project, the term dementia will be used to refer to these progressive and irreversible disorders.

The stages of dementia are experienced through cognitive, behavioral, and physical decline beginning with mild memory loss, advancing through progressive mood and sleep disturbances, and eventually leading to severe impairment requiring assistance with all aspects of care (Garcia-Alberca, Cruz, Lara, Garrido, Lara, Gris, Gonzalez-Herero, 2013; Gibson, & Anderson, 2011; Rose & Lopez, 2012). The Global Deterioration Scale (GDS) (Reisberg, Ferris, DeLeon, & Crook, 1982) is used to describe the seven global stages beginning with no impairment, very mild decline, mild decline, moderate decline, moderately severe decline, severe decline, and very severe decline. These stages are not experienced in isolation by the person with dementia, but rather they are interrelated within the spousal couple's relations and patterns of communication, coping, and resilience. Understanding the ways that older couples cope and make decisions requires differentiation between the stages of illness trajectory of dementia and the couple's transition through the stages (Rose & Lopez, 2012). During the moderately severe decline to the severe decline stages of the trajectory of Alzheimer's disease, transition in care becomes increasingly difficult for the spousal caregiver (Rose & Lopez, 2012).

The downward cycle of Alzheimer's disease is terminal and is expected to lead to the need for relocation for end-of-life care (Rose & Lopez, 2012). Robinson et al. (2012) determined that advanced care planning must be conducted at a time prior to the need for LTC placement. Assessment tools are providing for improved continuity of care and education

surrounding end of life care to support decision making of couples when one of the partners has been diagnosed with dementia (van der Steen, 2010). While living and dying in LTC are inextricably linked, the transition to care and preparing for this event is ameliorated by the development of key relationships in every day care (Goodman, Amador, Elmore, Machen, & Mathie, 2013). Sensitive planning of end of life care will enable couples to continue to have active and meaningful lifestyles and avoid aggressive interventions which may not alter the outcome (Ryan, Ingelton, Gardiner, Nolan, & Gott, 2009). Further understanding of the experiences of the older couple is required to assist with appropriate services to guide and support the transition when one of the partners relocates to LTC.

Experience of Dementia

Issues and strategies surrounding dementia care are most effectively understood when the experiences, of the individual diagnosed with dementia and of the care giver, are considered separately and together simultaneously as a couple (Braun, Scholz, Bailey, Perren, Hornung, Martin, 2009). Historically these experiences were explored in isolation and more recently researchers are conducting studies which are taking into account the interdependence involved in dementia care (Nolan, Davies, Brown, Keady, & Nolan, 2004).

Person with dementia.

The study of dementia care, with respect to the psychological and behavioral changes which occur throughout the trajectory of the illness, begins with an understanding of the experience of the person with dementia. Caregivers can establish timely and appropriate interventions when they understand the experiences of the person with dementia. The Progressively Lowered Stress Threshold (PLST) Model (Gerdner, Buckwalter, & Richards Hall, 2005) is used to provide education regarding stressors and behavior of the person with dementia.

The Functional Transitions Model (FTM) is used as a practice framework guide to assist caregivers with minimizing the disability associated with dementia, while anticipating the progressive functional decline (Slaughter & Bankes, 2007). Nygard (2006) encouraged varied approaches to interpret observations and stories relayed from individuals living with dementia. The physical elements of the senses and nonverbal gestures, with a focus on the interaction between the participants are the concepts of embodiment. The opportunity to understand the lived experience of dementia as it exists for the couple may be heightened with use of the embodiment principles (Hyden, 2013). Exploring quality of life within dementia, as opposed to a disease model approach, underpins the use of embodiment assessment and interventions (Downs, 2013).

The concept of person-centered care (Woods, 2001) was built upon Kitwood's (1993) equation that considers dementia as made up of the influences of an individual's personality, biography, physical health, neurological impairment, and social psychology. In a study of quality of life predictors for the person with dementia, Menne, Judge, and Whitlach (2009) found the variables, within the individual's background and within the caregiving relationship, were determining factors of strengths and needs. A person-centered focus on the lived experience of dementia provides value for the individual living with the illness, but may not take into consideration the experiences within interpersonal relationships (O'Connor et al. 2007).

The experience of the individuals with dementia must be considered within the context of the caregiving relationships in which they live (Turner & Findlay, 2012) when their care is provided by family and friends. Schulz and Martire (2004) reviewed the literature surrounding the risks and subsequent interventions available to support caregiving of a family member who

has been diagnosed with dementia and have recognized the important role of health care providers in the assessment of these roles.

Family caregivers.

A number of variables have an impact on the care provided by family members to a person diagnosed with dementia. Considerable research has been undertaken regarding caregiving challenges and rewards experienced while providing care for family members diagnosed with dementia (Gibson & Anderson, 2011). From the time of diagnosis caregivers require support in adjusting to their role through the provision of education and services (Ducharme, Levesque, Lachance, Kergoat, & Coulcombe, 2011). Papastavrou, Kalokerinou, Papacostas, Tsangari, and Sourtzi, (2007) recommended further understanding of caregiver experiences in order to assist with enriched coping skills to manage the social and relational stresses that accompany the caregiving role. Heru, Ryan, and Iqbal (2004) determined the importance of appropriate assessment of family functioning as a factor affecting various caregiving roles. The issue of stigma, in relation to family caregiving, is becoming better understood through efforts of increasing awareness of symptoms as well as available supports and services (Werner, Mittelman, Goldstein, & Heinik, 2012). The caregiver's resilience and adaptation to LTC placement of their family member (Gaugler, Margriet Pot & Zarit, 2007) has been explored and the importance of providing services to fit the needs of the caregiver has been identified. Eloniemi-Sulkava et al. (2009) tested the effectiveness of a multicomponent support program for elderly couples living with dementia and determined that individualized services delayed institutionalization and did not increase service use or costs.

Limited research has been undertaken to understand the experience of the couple when one of the partners has been diagnosed with dementia. Even less study has been undertaken to

understand the older couple (Baikie, 2002) and their relationship (Davies, 2011) in managing their lives together after the diagnosis of dementia has been incurred by one of the partners (Hellstrom, Nolan, & Lundh, 2005). It is essential that health care professionals who provide support to couples living with dementia understand the experience – the goals, the challenges, the joys, and the disappointments of these couples. Lewis, Hepburn, Narayan, and Nelson Kirk (2005) stressed the importance of health care professionals having an understanding of the impact of the disease on the couple and the equally important consideration of the relationship of the couple upon the disease (Davies & Gregory, 2007).

Spousal caregivers.

In 2006, in Manitoba 68.7% of seniors 65-74 years of age and 45.2% of seniors 75 years of age or older, lived with a spouse or common-law partner (Centre on Aging, 2010). The first source of health and social support is typically the spouse (CIHI, 2011) and spouses are the predominant care providers for individuals with dementia (Davies, 2011; Hellstrom, Nolan, & Lundh, 2005).

Spouses experience caregiving differently from other caregiver groups (Baikie, 2002; Blieszner, & Roberto, 2010; Heru, Ryan, & Iqbal, 2004). Focusing on the dyadic relationship will not only lead to a better comprehension of caregiver stress, but will also help to develop effective therapeutic interventions to enhance dyadic well-being of afflicted couples (Braun, Scholz, Bailey, Perren, Hornung, & Martin, 2009).

According to Hellstrom, Nolan, and Lundh (2007) couple relationships may evolve along three possible paths; working together, working separately, and working alone. The impact of the couple's relationship on the diagnosis of dementia is a facet that is distinct from the impact of dementia upon the relationship (Davies & Gregory, 2007). The relationship of caregiving may

benefit from consideration of the definitions of the couples changing roles and ways that these roles are explored in the context of the marital relationship (MacQuarrie, 2005). Health care providers may be able to assist the couples to express themselves and better manage the hurdle of stigma associated with the diagnosis of dementia and the trajectory of the disease (Hellstrom & Torres, 2013).

The lived experience of these couples is beginning to be explored. The couple's history together is important context for understanding their relational sensitivities and coping strategies within the changing landscape of dementia (Baikie, 2002). The early stages of dementia may allow for the 'us identity' of the marital relationship to continue (Davies, 2011). The trajectory of Alzheimer's disease will have an impact upon the couple's ability to maintain their relationship (Hellstrom, Nolan and Lundh, 2005). Couple's experienced phases of sustaining couplehood, maintaining involvement, and moving on (Hellstrom, Nolan and Lundh, 2007). Braun, Scholz, Bailey, Perren, Hornung, and Martin (2009) studied couples at a time when the person with dementia was able to participate in the construction of understanding the experience of the couple. This research study is conducted at a point where only the perspective of the caregiver is explored, but considers the importance of previous learning from the person with dementia. Relational patterns play a part in determining caregiving abilities and needs (Lewis, Hepburn, Narayan, & Nelson Kirk, 2005).

Researchers have focused on the impact of the disease on the couple (Baikie, 2002) rather than the impact of the couple on the disease (Davies, 2011; Hellstrom, Nolan and Lundh, 2007). The older couple's experience at the time of diagnosis has been explored to better understand their preferences regarding disclosure of the diagnosis (Hellstrom & Torres, 2013). Investigation into couple's communication patterns, within early-stage dementia, has led to the development of

a framework to assist in better understanding the role of resistance as a protective factor for the maintenance of the couple relationship (Clare, 2002). Further understanding of spousal caregivers' perspectives of before, during, and after their partner's relocation to LTC will assist in developing services within the health care system to support the couple living with the disease (Blieszner & Roberto, 2010; Nolan, Davies, Brown, Keady, & Nolan, 2004).

Spousal Transition

Consideration of the contextual importance of the relationship, multiple perspectives, and the evolving nature of the situation may provide couples' with some ability to make adjustments and cope with the trajectory of dementia (Robinson, Clare, & Evans, 2005). Assisting caregivers to better understand the perceptions of their spouses who have been diagnosed with dementia may lead to the development of more effective interventions for managing transition within the changing relationship (Lewis, Hepburn, Narayan, & Nelson Kirk, 2005; Lyons, Zarit, Sayer, & Whitlatch, 2002). Spousal caregivers, who used disengagement coping strategies such as problem avoidance, wishful thinking, self-criticism, and social withdrawal, resulted in their partners demonstrating more severe and frequent behavioral and psychological symptoms. Those care partners, who employed engagement strategies such as problem solving, cognitive restructuring, expression of emotions, and the use of social supports, managed change more successfully (Garcia-Alberca, Cruz, Lara, Garrido, Lara, Gris, Gonzalez-Herero, 2013). Spousal transition involves the ongoing process of achieving, maintaining equilibrium, and seeking a balance between hope and despair, as well as optimism and realism within the early-stage of dementia (Clare, 2002). There is a gap in the literature exploring the transition of the spousal relationship in the later stages of dementia. O'Shaughnessy, Lee, and Lintern (2010) stressed

that service providers must improve their understanding of the spousal role, as caregiver, so as to support the relationship and see it as an aspect of the individual's identity.

The experiences of the spousal caregivers and their partners with dementia are explored individually and within the context of the couple. This research may inform health care professionals to better assist couples in coping with the trajectory of the disease and attaining a better of quality of life throughout the spousal transitions. In the later stages of dementia, the perspective of the spousal caregiver is the focal point for understanding transition through their perspective and their perceived perspective of their partner, as well as the two as a couple unit. Lived experience is shared and understood through interview dialogue that allows for the creation of interpretive language which condenses and intensifies the meaning of the phenomena (van Manen, 1997). The following findings are the result of carefully constructed questions and interpretation of the dialogue used to explore the couple transition within dementia and relocation of the partner to LTC.

Chapter 3 – Research Method

Methodology can be described as the theory behind the method (van Manen, 1997). This researcher's methodology is underpinned by personal and professional values. As a psychiatric nurse and researcher I believe philosophically in the principles as espoused by Martha Rogers (1970) in that human beings are unitary beings who are more than and different from the sum of their parts. I believe that a mutual rhythmical interchange with the environment identifies human beings by the patterns they create. I consider that change is unidirectional and unpredictable and human beings are systems which move through stages of organization and disorganization to more complex organization. The application of these principles is ever expanding within my thinking and has influenced the development of this research project.

Research Design

This qualitative study was based on the methodological principles of hermeneutic phenomenology (van Manen, 1997) which provided the basis for the process of conducting the interviews, with the caregiver spouses, and the analysis of the data. The interviews were recorded and transcribed and then explored in conjunction with my field notes, which included observations of the participant's demeanor, environment, and related contextual elements of the dialogue (Polit & Beck, 2012). The phenomenological process was used to explore the experience of the caregiver through the use of open-ended questions. The analysis consisted of a stepwise approach to delving into the written dialogue in order to portray evolving themes through the interpretative tasks of organizing the dialogue from the data.

The research questions were designed to gather understanding of the experience of the caregiver spouse, the partner with dementia, and the couple unit through the perspective of the

spousal caregiver. The interview guide was used to initiate the conversation with the spousal caregiver and was adjusted to facilitate the conversation about the experiences being shared.

Psychiatric nurses take a non-reductionist view of the human experience, seeking development of knowledge to understand deeper meaning in order to create a foundation for change and improvement in health services (Holm & Severinsson, 2011). The interviews were recorded and transcribed and then explored in conjunction with my field notes, which included observations of the participant's demeanor, environment, and related contextual elements of the dialogue (Polit & Beck, 2012). The phenomenological process was used to explore the experience of the caregiver through the use of open-ended questions. The analysis consisted of a stepwise approach to delving into the written dialogue in order to portray evolving themes through the interpretative tasks of organizing the dialogue from the data.

The Participants

A purposive sample was used to conduct this phenomenological study. The proposed plan was to interview about 5-8 spousal caregiver participants who resided in or near a rural city on the Canadian prairies. In keeping with the research plan, participants were the caregiving spousal partners where one of the partners had been diagnosed with dementia and was presently residing in LTC. These participants were aged 60 years or older. Each caregiving partner had been residing with his or her spouse prior to the spouse's relocation to LTC. Caregiving spouses were maintaining their relationships with their spouses following the LTC placements.

The researcher initiated contact and met with the health region's LTC facility coordinators, the waiting placement social worker, the Alzheimer Society program manager, and the Home Care case managers to explain and discuss the research project. The researcher explained the process of invitation and reviewed the Letter of Invitation (Appendix A), as well as

the consent process and the Consent Form (Appendix B). The Letter of Invitation and the Consent Form documents were printed on Brandon University letterhead. The facility coordinators were requested to give the Letter of Invitation to spouses who met the criteria for inclusion in the study. Spouses were included if they a) were male or female aged 60 years or older, b) were living in the rural prairie city or on a farm near the city where the study was being conducted, c) had a marital partner who had relocated from their home to a LTC facility within the past 18 months; and d) in the assessment of the coordinator would be able to share their stories.

Data Collection

The interviewer used a semi-structured interview guide (Appendix C) which was adapted as the study evolved. Intuition and sensitivity fundamentally directed the moral commitment and encounters with the participants as the lived experience was explored through the relationships established between the researcher and the participants (van Manen, 1997).

Interviews were scheduled at the convenience of the participants and held in their homes. Two interviews of approximately one hour each were completed with each of the participants. The initial interview with the spousal caregiver was used to explore the current and retrospective experience of transition from residing with their partner diagnosed with dementia through to their partner relocating to LTC and their relationship as it continued to exist. The second interview provided the researcher with the opportunity to clarify information from the initial interviews, as well as encourage further information to be shared. In accordance with the *Tri-Council Policy Statement 2* (TCPS2, 2010), consideration of the physical needs of the elderly population were factored into the research project. The use of large print and layperson terms were used in the Letter of Invitation (Appendix A) and Consent Form (Appendix B). When

establishing the interviews, I deliberately arranged the timing within the participants' usual daily schedules so as to allow them the best opportunities to share their stories. While together during our meetings, I was cognizant of their non-verbal cues of physical or emotional discomfort and used empathy and compassion in delving into the topics of discussion. Also, I was flexible with external considerations such as incoming phone calls or visitors.

Within phenomenology, field notes are used as an observational interpretation of context which is not shared in the verbal dialogue of the story (Streubert & Carpenter, 2011). Aspects of the participant's environments, the backdrop and background of the shared experiences, as well as their body language and presentation, were written in notes shortly after the interviews to allow the researcher to apply these observations within the context of reading the dialogues and explicating themes.

I practiced from a mindful approach (Djikic, Langer, & Fulton Stapleton, 2008) within the dialogue between the participant and researcher. Being mindful in this manner is a conscious effort at awareness and checking of my own prejudices and stereotypes of elderly people. The encounter of exploring the phenomenon was a shared experience and the interpretation is presented within this multidimensional view throughout the discussion of the findings of this research project.

Data Analysis

The transcriptions were read and reread, followed by writing and rewriting; the whole and the parts as one (the individuals, the couple, the parts of their experience and their whole experience). Themes were explicated by determining meaning that captured the phenomenon of the experience of the transition of living with dementia and relocation to LTC. Themes are elements of the phenomenon and without them the phenomenon would not be the same (van

Manen, 2014). A manual process analysis and thematic coding involved printed versions of the transcriptions highlighted and marked to indicate phrases and statements of importance. These clues in the data were rewritten into grids and then overlaid with the same model from other interviews in order to determine areas of similarity and difference. From this repeated task of reduction, the intricate pulling apart and putting together (van Manen, 1997) facilitated the development of themes that could be determined as existing within the phenomenon of transition. This researcher's experience as a clinician who works with individuals and couples, could have influenced the conversation and analysis. However, bracketing was used by the researcher to suspend my beliefs and understanding regarding previously learned encounters in order to study the essential structures of the experiences being presented in the dialogue with the participants.

This research followed the methodological structure described by van Manen (1997) consisting of a dynamic interplay of research activities. This project began with a desire to better understand the phenomenon of transition of couples living with dementia and the relocation of one partner to LTC. The investigation of this experience was delved into through conversations with those who have lived and are living the reality, rather than as a conceptualization of the events. The dialogue was interpreted through creating and reflecting upon the essential themes which characterized the phenomenon. Description of the phenomenon was obtained through the art of writing and rewriting the textual dialogue, while maintaining a strong orientation to the phenomenon. Balancing the research context by considering the parts and whole of the experience as described by the participant underpinned the discussion of the existential concepts of temporality, a subjective experience of time; spatiality, existing in our day to day lives;

corporeality, or lived body; and relationality, our interpersonal space, as these concepts exist within the phenomenon of transition.

Ethical Considerations

The research project was commenced upon receiving a Brandon University Research Ethics Committee certificate (Appendix D) as well as a letter of approval from Prairie Mountain Health Ethics Research Committee (Appendix E). The timeline (Appendix F) for this project was arranged in accordance with these approvals.

The interviews were undertaken only upon the completion of the verbal explanation of the project and its purpose and the signing of the consent form. The project, procedure, and ethical considerations were explained to each participant. Each participant was provided with a completed copy of the consent form and a copy of each consent form was retained by the researcher. The participants were encouraged to respond only to the questions they were comfortable answering. They were reminded that their participation was voluntary and they were told that they had the right to withdraw from participation at any time (TCPS2, 2010). The consent form included information regarding the purpose of the research, handling of the data (including recording, storage, and access to the data), as well as sharing of the findings in order to demonstrate anonymity, through the use of coding and pseudonyms; and confidentiality, which is kept through professional conduct and private use of the data. The participants were made aware that their participation would not affect any current or future health services. The participants were ensured that no financial costs would be incurred through their participation. The participants were made aware that their information would be shared as part of discussions toward the development of future policies and practices to better support the needs of individuals living with dementia, their spousal caregivers, and the couple as the unit of care.

The participants were informed of the processes by which their identities would be kept confidential, through the use of coded numbers on transcription documents and pseudonyms within written text. In this process, direct identifiers were removed from the information and replaced with codes. Participant names are stored separately and under password protection. The researcher is the only person with access to the code (TCPS2, 2010). Findings were aggregated and identifying data were removed to ensure that individual participants would not be identified.

Fulfilling the ethical duty of maintaining confidentiality is essential to the trust relationship between researcher and participant, and to the integrity of the research project (TCPS2, 2010). The computer files and transcripts of the conversations were kept confidential and accessed only by the researcher, thesis supervisor, and the transcriber. The computer files were saved on a flash drive and stored with the written notes in a locked filing cabinet. A confidentiality agreement (Appendix G) was signed by the transcriber. The electronic files will be erased and the paper copies will be shredded as soon as the research is completed and the findings have been disseminated.

The principal goals for dementia care are: early diagnosis; optimizing physical health, cognition, activity, and well-being; detecting and treating behavioral and psychological symptoms; as well as providing information and long-term support to caregivers (Alzheimer Society of Canada, 2010). The purpose of this project is to be able to gather and share information with organizations involved in program and policy development related to the needs and priorities of older couples living with dementia.

This phenomenological research design is well suited to explore the experiences as described from the perspective of a spousal caregiver whose partner has been diagnosed with

dementia and has recently relocated to LTC. It is the hope that participants find comfort and purpose in sharing their stories, while reflecting upon this transition as individuals and as couples. This researcher's task is to generate clear, systematic, and accurate themes, which reflect both unique and common experiences, and demonstrate this valuable information as beneficial to the future development of policies and practices aimed at supporting couples living with dementia in general and those transitioning to LTC in particular.

Chapter 4 - Findings

The research findings include demographic details, information reported by the caregivers, and observations made by the researcher. Field notes in the form of observations and interactions with the caregivers provided further information for analysis. The couples' demographic characteristics include: their ages, the length of time they have been together, the date of diagnosis of dementia, and their living arrangements in relation to the diagnosis and planning for relocation of the partners with dementia from their homes to LTC. Themes evolved from the information regarding the factors leading to the need for relocation to LTC, managing the relocation, and adapting to life after the relocation, with respect to changes that occurred in their physical, social, and emotional lives.

Demographic Details

Participants of the study were caregivers of spousal partners who were diagnosed with dementia and recently relocated from their homes to LTC facilities. Coordinators with local LTC facilities, Home Care, and the Alzheimer Society provided Letters of Invitation to potential participants. Seven people responded to the letters and all participants fit the inclusion criteria for the study. Six wives and one husband were interviewed as spousal caregivers of partners who had been diagnosed with dementia. Two interviews were conducted with each participant and all interviews were completed within a four month period.

Description of participants.

The caregivers who participated in the study ranged in age from 72 to 92 years of age with the average age being 79 years (See Table 1). The partners with dementia ranged in age from 73 to 94 years of age with the average age being 81 years. In all cases the caregiver was the same age or younger than his/her partner. The importance of recognizing and considering the

changing role and responsibilities of the caregivers, with regard to their age and the physical demands of providing care for their partners with dementia, became apparent during several of the interviews. None of the caregivers were employed or had other commitments outside of the home.

Table 1: Couple Demographics

Caregiver age	Partner age	Years married or living together	Years since diagnosis of dementia	Years from diagnosis to LTC
72	73	12	1.5	1
80	80	24	3	2
92	94	62	4	3
75	76	56	6	5
81	84	57	6	5
84	84	63	9	8
72	73	50	13	11.5

The number of years that participants were married or living together ranged from 12 to 63 years (See Table 1). Five of the seven couples had been married between 50 and 63 years. Caregiving spouses within two of the couples had been previously widowed and were in second marriages, of which one couple had been married for 24 years. The other one of these couples had never married but the partners had lived together for 12 years. Both of these two couples created blended families of now adult children. All but one couple had children. Variations existed within the dynamics of the children's support. Some of the children lived far from their parents' homes yet were involved and helpful. Some children lived in the same community but were much less engaged in support or care. The couple, who did not have children, had received support from their siblings and extended family.

Living arrangements.

Throughout the changes in their abilities to manage the trajectory of dementia, the couples made changes to meet their needs with regards to their living arrangements. Following the diagnosis of dementia, three of the couples made the decision to move to housing that provided them with better opportunity to manage the care that was required by the partner with the disease. When three of the partners relocated to LTC, the caregivers remained in their marital homes where they had resided for the previous 20 to 46 years. At the time of the interviews one of the caregivers was in the process of moving to a seniors' assisted living apartment following the relocation of her partner with dementia to LTC.

As shown in Table 1, the difference between timelines experienced by each couple reflects the variation in the trajectory of the Alzheimer's disease. The data were relevant to understanding the couples' experiences through the transitions from the time of diagnoses to the time when the couples could no longer manage to live together in their own homes.

The time from diagnoses until transition to LTC ranged from 1.5 to 11.5 years with an average of 5 years from diagnosis of dementia to relocation to LTC. One of the partners with dementia had early onset dementia, which is categorized as a diagnosis of dementia prior to the age of 65 years (Alzheimer Society Canada, 2015). The couple who experienced early onset dementia had been able to remain in their home for 11.5 years from the time of diagnosis. Other couples experienced much faster progressions of the disease. The shortest time from diagnosis to a move to LTC was 1.5 years.

The data from this study provided increased understanding of the unique and common lived experiences of each couple's transition from the time of diagnosis to the point of the partner relocating to LTC and their ability to remain being a couple while they were living apart.

Most of the caregivers described the transition from home to LTC as not being planned according to their wants and needs. Often the move came suddenly, at times as a result of other medical conditions experienced by the partner with dementia. The sudden needs for more care led to the paneling process, by which an individual is assessed for admission to a LTC facility to provide a safe and carefully designed environment, trained staff, and activity programs to meet the more complex care needs (Sherrell & Iris, 2005). The goal is for LTC facilities to be able to provide care that could no longer be made available in the couple's home. The paneling process involves an assessment of the physical, social, cognitive, and psychological capabilities and needs of the individual. The assessment is used to determine if personal care is an appropriate option for future care management and living arrangements (Winnipeg Regional Health Authority, 2015).

For five out of seven of the couples, relocations occurred as a result of primary medical conditions leading to hospital admission. Further assessment of needs related to dementia care determined that LTC was required. In these cases, the partner was not able to return home. Four of these five partners, whose initial moves were from home to hospital, were paneled for LTC immediately upon assessment of their physical and cognitive abilities. Support and advocacy from family members of the other partner with dementia helped to ensure that the assessment for personal care included information that the caregiver was unable to have her partner return home with the amount of care required. All of these partners were able to move to LTC within two to five months following the paneling process. Of the partners who left their homes as a result of primary physical conditions, one spouse with dementia had not relocated to LTC and remained on a unit in the hospital designed to provide care for those individuals who are waiting to move to a LTC facility once a room becomes available.

As a result of paneling, two of seven couples experienced relocations directly from home to LTC. Long-term community services through day programs and support staff, as well as a psychiatrist and geriatric assessment team, provided these couples with the opportunity to plan their partners' moves from home to LTC.

Understanding the Lived Experience of Transition

In phenomenological inquiry researchers seek to develop a language of being and becoming through understanding an intersubjective essence of the personal and collective history of events (van Manen, 1997). This method requires an ability to be reflective, insightful, sensitive to language, and constantly open to experience (van Manen, 2014). Information reported by the caregivers provided details and quotes which will be used to further describe the experiences of the couples during the trajectory of dementia and the resulting transitions to LTC.

This study was designed to better understand the lived experiences of spousal transitions prior to relocation decisions, through to the partner with dementia relocating to LTC, and the couple's adjustment to living apart. The participants were spousal caregivers who relayed their experiences, as well as their thoughts about the experiences of their partners with dementia. Participants also shared their perspectives of their experiences as couple units. Through analysis the researcher seeks to develop the overarching and imbedded themes within the experiences leading up to the need for relocation, managing the relocation, and adjusting to life after relocation to LTC. Essential themes are elements which are bound within the phenomenon. Without these elements, the phenomenon loses its fundamental meaning (van Manen, 1997).

Caregivers shared their experiences related to their partners' diagnoses and the challenges of the changing needs for themselves and their partners. The changes in task sharing, problem

solving, self-care, caregiving, coping, and communication affected the couples' relationships. Conversely, the transitions were influenced by the couples' existing relationships.

The essential themes of the lived experiences of spousal transition to LTC are reflected in the temporal categories of leading up to relocation, managing the relocation, and adjusting to life after relocation. Within the temporal sections the themes are further organized into subthemes of the spousal caregiver, the partner with dementia, and the couple unit. Thematic topics within these categories represent the parts and the whole of the phenomenon of spousal transition within dementia and related to relocation to LTC. The essential themes are grouped within the temporal and social themes, but that they not listed in any form of hierarchy.

Leading up to the need for relocation.

Cognitive, social, and behavioral changes associated with dementia often begin prior to diagnosis. The couples adapted to the changes and continued to function well within their own homes. Eventually, the progression of dementia symptoms and the challenges in providing a healthy and safe environment created the need for the partner to relocate to LTC. The experiences for the caregivers, the partners, and the couple units are interrelated throughout the transitions from living together as a couple in their own homes to the partners with dementia relocating to LTC.

The spousal caregiver.

Spousal caregiving is considered unique from other family caregiving relationships with loved ones diagnosed with dementia (O'Shaughnessy, Lee, & Lintern, 2010). The transitions for spousal caregivers involved emotional, social, and physical adjustments to the changes in care required for their partners. Caregivers were required to provide increasingly physical amounts of care for their partners and the ability to provide care was sometimes affected by the caregiver's

own frailty and health issues. The resources available to support the caregivers, their partners, and the couple were sometimes beneficial and sometimes unavailable. Education and awareness of dementia symptoms and care was helpful and was sometimes lacking for both the caregivers and the support system.

Increased requirements of caregiving.

Caregivers relayed their caregiving experiences as extensions of the existing patterns of care within their couple relationships. Caregivers shared their reflections on the increasing care needs of their partners and the adaptations in care made to attend to the variety of changes that occurred.

Assisting with activities of daily living (ADLs) were challenges met in the process of caregiving. Partners' abilities to care for themselves decreased and increasingly caregivers were required to assist with the daily care of nutrition, hygiene, continence, mobility, and sleep. Although ADLs are discussed here as separate aspects, weighing the activities together as a whole is a necessary consideration within the changes that occur in the trajectory of dementia.

Nutrition became an issue for four of the partners with dementia in different ways and required the caregivers to develop creative methods for managing these concerns. One of the caregivers found it necessary to monitor nutrition by keeping minimal amounts of sugar available in order to keep the partner from over indulging with sugar in coffee. The caregiver stated that as her partner's memory failed, he lost the awareness of having had lunch or a snack recently. The caregiver placed items in alternate cupboards to address the issue of frequent returning to the cupboard for cookies or bread and jam. The caregiver discovered that having the partner believe that there was no food to be had worked better than denying the food and creating an argument. Another caregiver made accommodation for the partner to eat at the lounge chair

with a small table when cooperation to move to the kitchen table at meal times was lost. Two of the caregivers provided food that was palatable and easy to manage without the use of utensils as the remedy for assisting their partners to achieve good nutrition. Caregivers helped partners to achieve good nutrition by knowing their likes and dislikes and making accommodations to their menus.

Assisting with daily hygiene and grooming became a necessary part of the caregivers' daily routines. Most of the caregivers indicated that their partners retained the ability to shower when they were prompted. Some of the partners required supervision and direction with the task of showering, but they were cooperative. When one of the caregivers could not convince her partner to use the shower and he chose to have a bath instead, the caregiver was required to call on her brother-in-law to help the partner out of the bathtub. Although this caregiver had family support to assist with bathing care, she was unsure how her partner felt about the situation. This same behavior had been repeated many times and the partner would not or could not verbalize thoughts or feelings on the matter. One caregiver could not convince her partner to shower or change clothing for as much as five weeks prior to his relocation from home.

Most of the partners had maintained their ability to dress themselves and some required direction and assistance from their spouse. Caregivers were aware of their partners' wants and needs regarding comfort of clothing for fit and for warmth or coolness. As long as the clothing that the partner chose was appropriate for the weather, the caregivers did not concern themselves with unimportant details of color or style. One caregiver reported that during the last year her partner lived at home he was unable to dress or shave himself but he cooperated with her efforts to assist. A caregiver's efforts to help her partner shave presented difficulty when she could not get him to sit in a place where she could plug in the razor. Having a daily shave was not

considered to be as important as bathing and dressing in clean clothing. The caregivers reported choosing their battles regarding hygiene issues.

Most of the caregivers reported that their partners had maintained the ability to be continent despite altered mobility and cognitive capacity. Incontinence became a concern for two of the partners, increasing the need for caregivers to assist with bathing and additional laundry. One partner cooperated with the need for wearing adult incontinence underwear. One caregiver persuaded the partner to use the underwear in order to provide peace of mind for the caregiver and dignity for the partner. The caregiver's ability to address the issue of incontinence was discussed with extended family early in the onset of dementia and unmanaged incontinence was determined to be a definitive factor in the need for relocation.

Most caregivers were required to make alterations in daily routines to manage their partner's decreasing mobility in order to provide the best care for overall health. The physical layout of the home was converted to provide the partner with normalcy of daily activities. Furniture was moved to eliminate the use of stairs, as well as decrease distance for the partners to move about the home, and provide ease of use for the partners. At the same time, caregivers recognized and encouraged the importance of mobility as part of a healthy lifestyle. Modifications were made to partners' previous tasks and chores to allow the opportunity for them to continue to contribute to the function of the home. Some of the partners continued with activities such as sweeping the garage, light yard work, putting away dishes, setting the table, and folding laundry which were helpful and meaningful contributions to household chores. Some partners' decreased mobility did not allow them to participate in any household chores. Tasks and chores that required more mobility than partners could manage became the responsibility of the caregivers. One caregiver informed of now sharing the chore of grocery

shopping. Constant supervision and additional time were required for the partner to be included in this task. Cooking meals, vacuuming, taking out the garbage, and cleaning bathrooms were some of the tasks that had become a shared or sole responsibility for most caregivers. Some tasks like lawn cutting, painting, repairing, shoveling snow, and deep cleaning were hired out by the majority of the caregivers. Some caregivers had family members and neighbors who assisted with these household chores.

Ability to do physical activities lessened and caregivers assisted with accommodations to provide opportunity for the partners to join in at a lesser degree than previously. One of the couples continued to attend curling and bowling. Partners' abilities were addressed with less strenuous engagement in the activities and assistance as needed. Another of the couples had always walked together and they were able to continue with daily walking up to the time the partner relocated to LTC.

Sleep disturbances for the partners became problematic in one form or another for the majority of the caregivers. Mixing up days and nights was a particular problem for two of the partners and presented difficulty in caregiving. A caregiver described the partner being up and showering as many as four times during the night. The disrupted sleep pattern was a concern for them until the partner relocated to LTC. The caregiver described this issue of sleep routine problems as one that cannot be assisted in the home and made the suggestion that respite away from home for a week at a time may be helpful for the caregiver to get some sleep and regain strength to continue to give good care. Another caregiver struggled to have the partner get up in the day and sleep at night, interrupting rest and nutrition for both of them.

“He got so that he'd get up about supper time. Well that meant he hadn't eaten all day and then he got into that chair and he'd still be there at 2 o'clock in the morning. I couldn't get him to go to bed.”

Medication was beneficial in regulating one of the partner's sleep patterns. Two partners were reported to sleep late into the morning and take naps in the afternoon. Altered sleep patterns made for interruptions in day-to-day events and chores that the caregivers still were required to complete. Disrupted sleep for lengthy periods of time and increasing amounts of physical and emotional strain created stress for the caregivers to the point of feeling exhausted and overwhelmed. The accumulation of this stress impacted caregivers' provision of care for partners while attempting to maintain their own health.

Frailty and health issues.

Dementia did not occur in isolation from other medical health issues for the caregivers or their partners. Partners' pre-existing health issues were combined with the changing physical demands associated with dementia. Caregivers' increasing frailty, accompanying aging, and their own health issues complicated their abilities to adapt to the increasing amount of care required by their partners. Caregivers had grown accustomed to their changing abilities prior to the onset of dementia symptoms. Additional adaptations were required for caregivers to meet their own needs as well as the changing needs of their partners. Continual adjustments to the changes within the daily care were made until the partners' needs overcame the caregivers' ability to manage. A caregiver shared the experience of trying to provide increasing amounts of care for her partner at home,

“You've got to be younger and stronger to deal with that [physical care], I didn't know how.”

One of the caregivers received a diagnosis of breast cancer and underwent treatment at the same time her partner was diagnosed with dementia. Dementia had not yet affected her partner's abilities during this time and the dementia was of a nature that required little intervention for his care. The caregiver reflected that throughout her recovery she began to feel the impact, of increased care needs for her partner, upon her own health and wellness. The progression of her partner's dementia symptoms was coupled with her compromised health status and desire to avoid assistance. With new found insight, the caregiver now recommends that caregivers seek all the support that is available as early as possible.

While living together after the diagnosis of dementia, there came points in time when activities of daily living and health needs became difficult tasks to manage. Eventually and to some degree, all of the spousal caregivers were unable to meet these needs on their own.

Use of supports.

Caregivers made initial contact with the health care system through their family doctors, as the symptoms of dementia began to occur. Some of the partners' symptoms were picked up by family doctors during examinations for other physical symptoms. Some caregivers had noticed changes related to dementia with their partners but did not seek medical attention. One partner was the first to recognize memory issues and request assessment. The family doctor provided assessment and initiated the referral process for additional health care services and supports.

Caregivers accessed supports available through family doctors and the health care system, as well as the supports of family members and friends. The caregivers described variations in the amounts of awareness, input, and supports they received from their family doctors and the health care system, as well as family members and friends.

One caregiver and an adult child began to recognize dementia symptoms in the partner associated with memory, safety, behavior changes, and increased irritability. The caregiver and son attempted to discuss these changes with the partner, and the partner denied any problems. The caregiver and son then decided to meet with the partner's family doctor to initiate assessment, specifically requesting the family doctor to not inform the partner of their concerns. The family doctor agreed to cooperate with this plan. Upon attending the doctor's appointment the partner had been informed by the doctor that family previously approached with concerns regarding dementia. The partner returned home angry with the caregiver. The caregiver did not seek further input from the partner's doctor. The caregiver's doctor was able to provide support and guidance for the caregiver. Discord with the partner's doctor did not provide for complete care for the partner and the caregiver.

One caregiver, having professional experience and psychiatric nursing support from a daughter, requested a referral to psychiatry and mental health services early in the diagnosis to access thorough assessment and treatment planning. This caregiver stressed the importance of starting early to establish a health care team that is on board with appropriate care for dementia.

Four of the partners attended daily programming specifically designed to provide care for individuals living with dementia. The supervision and activities at day programs provided stimulating and safe environments for the partners. Caregivers used this respite time to attend to errands and household chores. Staff at the day programs gave input and support to the caregivers by providing feedback on the partners' daily functioning. The caregivers reported that this service and support provided them with the ability to manage together in their own homes for longer periods of time.

Home Care and Mental Health Services provided in-home supports and respite for two of the caregivers. The caregivers valued the interaction that their partners received during the respite time. The partners engaged in conversations and activities that reflected their interests, providing diversity and stimulation in their days. The supervised time with a respite worker provided one of the caregivers an opportunity to run errands. As much as it was appreciated by one of the caregivers, the respite time did not allow for the opportunity to accomplish much work and did not provide time for relaxation or self-care. One caregiver expressed concern over the lack of Home Care staff's ability to provide care for her partner.

"I had Home Care coming for a while. They just came once a week. To give him a bath. Well, the girl would come in and sit there [pointing to where I was sitting] and he'd be there [indicating the lounge chair], she said G would you like me to give you a bath? He'd say no, I'm fine. Now if she had gone over there and said G, would you stand up, he would've. And come with me. He would have. So and never did get a bath. And, uh, Home Care, the head of the Home Care at that time, she said to me don't worry. Nobody ever died from not having a bath. Well, he'd had five weeks straight without even having his clothes off."

The caregiver expressed concern regarding the training and abilities of the support workers and the effectiveness of Home Care policies and procedures. The caregiver shared her belief that she could still be caring for her partner at home if assistance with getting him in and out of bed, bathing him, and dressing him could have been met by the Home Care support workers.

Family members and friends were described as being helpful in assisting the caregiver with the increasing tasks of providing care. Family members helped with household chores and errands. Family members also spent time with the partner and provided the caregiver with the opportunity to complete tasks or to rest. Family members assisted the caregivers with adopting new skills to accomplish tasks that had once belonged to their partners. Financial management, having the oil changed in the car, and household chores such as laundry, small repairs, and cooking were some of the tasks that family members and friends were able to assist caregivers in

learning. Sometimes the family members and friends offered support through assisting with getting groceries or attending to household tasks. Sometimes the caregivers needed to ask for assistance and even then they may not have received the help they required from family members.

The Alzheimer's Society Caregiver Support Group was helpful for one of the caregivers to share experiences and learn ways to care for herself and her partner. For most of the caregivers, self-care was not a usual habit in their lives prior to the onset of their partners' dementia. Awareness of self-care was present to some degree for each of the caregivers. Using supports to provide for self-care was difficult for most of the caregivers to adapt into their lifestyles.

Education and awareness of dementia.

Caregivers' knowledge of the symptoms of dementia provided them with some abilities to cope with the changes their partners were experiencing. For the most part, previous exposure or formal education regarding the symptoms of dementia meant that caregivers were not caught off guard by the cognitive, emotional, and physical changes exhibited by their partners. For some of the caregivers, additional knowledge and awareness of symptoms may have been helpful in managing care and accessing supports. One caregiver expressed beliefs that were felt as a result of the diagnosis of dementia,

"...even though you read that information, you feel helpless, not knowing what to do...I just felt like it was inevitable...like there's no, there was obviously no solution for it...it was just something that once you got it, you got it."

Education and awareness for family members and friends was an issue of concern for some of the caregivers. A number of caregivers shared experiences of family members and

friends being helpful and understanding. Some caregivers were knowledgeable themselves and assertive in seeking connection and assistance from family members, friends, and services.

Some caregivers had family members who worked in the health care system and had been an asset in sharing knowledge of services and supports. One caregiver shared frustration at children being nurses and not being of support. Another caregiver was saddened at the decreasing amount of visiting from children and grandchildren which had occurred as the disease had progressed. The caregiver recognized that the partner may not remember the family members or recall the visits. The caregiver expressed hurt at the lack of connection with family. Pre-existing family dynamics may have influenced current relationships as they existed at the time of the interviews.

One caregiver described the experience that occurred as a result of the diagnosis of dementia for the partner,

“You seem to lose a lot of people that you thought were your friends when this happens. I guess they don’t know what to do or what to say and they just don’t show up.”

The caregiver had not discussed this concern with Mental Health or Home Care workers who had provided care for the partner. No assistance was received to help with this concern.

The interrelated needs of the caregivers and their partners are indicated in the themes that relay the experiences of spousal transition. Caregivers relayed their perception of their partners’ experiences leading up to the need for relocation.

The partner with dementia.

Caregivers’ perceptions of the experiences of their partners was a reliable source of information for the purpose of this study. Previous experience with their partners’ cognitive,

social, and behavioral functioning provided intimate knowledge with which the caregivers made choices for care.

Changing activities of daily living.

Instrumental Activities of Daily Living (IADL) are those activities which affect an individual's independent functioning and change throughout the trajectory of dementia. These skills include using the telephone, traveling, shopping, preparing meals, doing housework, taking medicine, and managing money (Sherrel & Iris, 2005). The caregivers described experiences of their partners' abilities having been lost over time, requiring additional observation and intervention from the caregiver. The partners' awareness of their functioning varied. Most partners proceeded without much discussion of the changes that were occurring as their caregivers adjusted to the partners' needs with compassion and understanding. Some partners demonstrated insight and requested assistance to deal with the deterioration in their abilities. Other partners minimized or denied the changes that were occurring as a result of the trajectory of dementia.

The couples had shared the responsibilities of household management, from daily and seasonal tasks, through to financial accountability. As partners' capabilities to make independent or mutual decisions regarding household management and planning declined, the shared responsibilities became the responsibility of the caregivers. Adaptations in care evolved subtly without much problem as the caregivers adjusted to the continual simple and then complex deficits in their partners' abilities to manage IADLs.

Changing issues related to daily living activities accumulated over time and led to the eventual need for relocation to LTC. Additional issues of safety impacted the couples' abilities to manage together in their own homes.

Safety issues.

Driving safety became an issue for six of the seven partners who had previously driven. Four of these partners recognized their decreased memory, focus, and physical abilities to drive and voluntarily gave up driving. Couples, where the caregivers had the ability to drive, reported that they adapted to the change with little inconvenience.

Two of the partners were angered and frustrated with the loss of their driver's licenses. One partner had multiple accidents and the driver's license had been revoked. One caregiver attended a family doctor appointment with the partner to report concerns of unsafe driving. Although the doctor had agreed that the partner should not be driving, it took three weeks for the official letter to come in the mail.

“He was pretty upset about losing his driver's license...I wouldn't have told him myself, he wouldn't have believed me.”

The caregiver reported three very long weeks of avoiding the need to drive anywhere. The caregiver did not drive herself and was required to make alternative arrangements with neighbors or manage with the groceries so as to avoid the need for her partner to drive.

The partners' wandering from home and losing the ability to find their way home became serious safety concerns for three of the couples. In both situations, the help of family members and neighbors was necessary to ensure the partner was monitored and returned safely home. One of the caregivers informed of having to keep a very close watch on her partner leaving the house to check on the garage. This issue had become a concern for the caregiver especially during the night.

The issue of falling became a potential safety concern for one of the couples. The caregiver described the partner as falling either when getting into or out of bed. Initially the

caregiver had been able to assist the partner to get around. Together, the couple lost the ability to manage the partner's mobility and the caregiver would call 911 for the ambulance attendants to assist with helping the partner back into bed or to the chair.

Most caregivers reported progressive decreasing of their partners' cooperation with the care as part of the trajectory of dementia. Two of the caregivers reported that their partners had begun to display signs of physical aggression prior to relocating to LTC.

None of the couples had safety issues regarding the use of the stove or other appliances that could be potential safety hazards for the partners and ultimately the caregivers. One of the caregivers described the partner's reluctance to relinquish chores and tasks involving heavy or motorized equipment. The caregiver was required to closely monitor activity to intervene before the partner could attempt chores such as cutting the grass, trimming hedges, or using a snow blower.

The tasks that caregivers were unable to accomplish were completed with the help of family members and neighbors or by hiring assistance for these jobs. Some of these tasks were eliminated when the couples moved into living arrangements which did not require these chores.

Behavioral and social changes.

The partners displayed changes in their personalities and demeanor that were uncharacteristic of their previous selves. Confusion leading to aggression was the primary behavioral and social change that contributed to the need for relocation to provide safety and security for both the caregivers and their partners.

Support from family members and education from professional health staff provided encouragement for caregivers to recognize when agitation and aggression were to the point of becoming a safety concern. Caregivers' understanding of these potential symptoms of dementia

allowed them to make choices regarding relocation in the best interests of their partners. Making the choices for relocation before their behaviors became dangerous to themselves or others was a way to help their partners maintain their dignity.

A partner began throwing dishes and forcefully moving about chairs in their kitchen. The caregiver attributed this behavior to her partner being overwhelmed with the tasks. She attempted to manage this behavior by providing fewer tasks and giving basic instructions. When the behavior was occurring, the caregiver would remove herself from the situation and wait for her partner to settle.

Another caregiver made frequent contact with day program staff to ensure that her partner was cooperative, as a measure of monitoring his behavioral and social abilities. The partner was able to use a cab to attend day program each day. One day he became confused and agitated and jumped out of the cab at a stop sign. When the partner yelled and kicked at the car, the driver called 911 for assistance. At that point, the caregiver made the decision to pursue the relocation from home to LTC.

Decisions made by the caregiver had significance for themselves, their partners, and the couple units. The caregiver, partner, and couple were considered simultaneously throughout the transitions in care.

The couple.

Couples attempted to normalize changes that occurred with dementia and reestablish patterns of interaction and management in order to continue to function in their own homes. The changes within the dynamics of the couples' relationships were not the indicators of the need for relocation to LTC. The caregivers informed that they would have had their partners remain together with them in their own homes as long as their health and safety needs were being met.

Couplehood.

Caregivers revealed the emotional strain that they felt in coping with the changes in their partners' cognitive and emotional functioning. Observing their partners' inability to engage in previous interests and ways that these changes affected the partners they once knew was very difficult. This experience was described as a sense of grief for the loss of the partner they had known and a sorrow for the resultant changes in their relationship. The caregivers shared ways that they managed to help their partners adjust to these changes. The caregivers provided alternate but related tasks for their partners, like sweeping and organizing the garage as opposed to building. The caregivers participated in shared interests in ways that engaged their partners. Sometimes new interests were attempted to replace those that were not able to be enjoyed any longer. And finally, the caregivers accepted their partners' interests had changed and supported them to be less active.

The trajectory of dementia and the transitions in relationships affected the communication that occurred between the partners with dementia and their caregivers. As the partners' abilities to verbally communicate their wants and needs deteriorated, the caregivers relied on their knowledge of their partners to anticipate their partners' wants and needs.

The elemental theme of the couples' pre-existing relationships underpins the challenges and adaptations which reconstructed the spousal transition within dementia. Relationships transformed as the progression of dementia occurred. As the partners' fluctuations in cognitive functioning, language skills, and social behavior occurred so did the changes in relationships with the people in their lives, primarily with their spouses. The caregivers again described feelings of sadness and grief at the loss of the partner they once knew as a father, mother, brother, sister, aunt, uncle, or a friend.

The challenges of dementia impacted the ways in which the couples functioned as a unit. Loss of independence for the partners with dementia resulted in increased dependence upon the caregivers. Their relationships shifted as the partners required more direction and supervision from their spousal caregivers. Caregivers' previous knowledge of their partners' likes and dislikes, habits, and tolerances provided them with more opportunity to make the adjustments with their interactions as smooth as possible. Partners with dementia sometimes indicated annoyance at being corrected and frustration at the limitations or guidance that was placed upon them. Caregivers shared their experiences of managing the changes in their partners' behaviors.

"He wouldn't cooperate at all which wasn't normal either." "It was hard to start telling him you have to do this cause I've never bossed him around before."

Variability in the caregivers' awareness and understanding of dementia led to compassion and confusion as these transformations occurred. Changes that presented challenges were reported to have occurred both slowly and suddenly. Sometimes symptoms were acknowledged by the partners and sometimes denied. The slowly evolving challenges were adapted into the couples' daily routines. The sudden changes were often met with feelings of being overwhelmed until a method of management or support was established.

The extra responsibility and energy required to manage the tasks of caregiving created some concern and frustration for the caregivers. The relationships between the spouses had shifted to those of caregiver and partner.

"He was getting to be like a child that you had to look after him."

"...it was like having a difficult child around, one you couldn't handle."

The caregivers expressed their sentiments regarding the changes in their relationships with their partners by using humor and compassion.

Relationships with family members and friends were maintained following the diagnosis and throughout the trajectory of the disease, as well as through transitions in care. Family members were available to assist with daily care needs, when they resided in the community, and were able to provide emotional support, when they lived at a distance. A decrease in the amount and quality of time that family and friends spent with one of the couples created isolation for the caregiver.

“I would hope that families in general would be more supportive, you know, it would be good if families could be made aware of the need to be there.”

The caregivers expressed their appreciation for the relationships they had with their neighbors who were often available to assist with the challenges of increased care. Most neighbors became involved at the request of the caregivers. Recognition that some of their neighbors were seniors themselves and the limitations upon their abilities to provide support was not lost upon the caregivers.

Caregivers learned to navigate interactions with acquaintances while on outings in order to provide comfort and dignity for their partners as well as the others involved. Interactions with all people in the couples' lives were affected by the diagnosis and trajectory of dementia as the transitions occurred for the caregivers and their partners.

Strengths and abilities.

Couples had shared mutual experiences of previously coping with various life events. Through this exposure the couples developed an underlying fortitude when it came to managing changes involved with dementia. Caregivers' decisions on behalf of their partners were made with deliberate awareness of the needs of each of the individuals and the couple unit at the same time.

Most of the caregivers had made independent and mutual decisions as part of the couple unit throughout the years. Adaptations to making decisions on behalf of their partners were described through stories of resilience, commitment, and practicality. The caregivers' attitudes were generally that of enduring life as it presented itself. Acceptance of the changes and readjusting previous ways of doing things afforded caregivers with the abilities to transition their roles as couples within the progression of dementia.

One of the caregivers described her role within the couple as less mutual and more distinctly separate from that of her partner,

"...he's the guy that used to look after everything...I did the cooking and the cleaning and all that but he looked after everything else...made the decisions and all and this is my job now."

Adapting with these changes required the caregiver to approach her partner in ways that she had not previously. She described having developed a comfort with the need to take control of the situation,

"...he was ok cause he didn't know I was managing him."

Confidence and resourcefulness in addition to respect and compassion for her partner were the strengths that this caregiver described in making adjustments to accommodate the changes as a result of dementia.

The experience of transition within dementia for these couples was not remote from their involvement in the rest of their lives. Life continued for the couples with varying degrees of interaction with family members and friends. The caregivers described handling the joyful and traumatic events with attention to their partners' abilities to comprehend the situations. Personal experience and knowledge of dementia were strengths used as tools by the caregivers throughout

the progression of the disease, while they remained together with their partners in their own homes.

Confidence, resilience, experience, resourcefulness, patience, and compassion were the foundational strengths and abilities that spousal caregivers used to cope. Relocation to LTC required these same strengths and abilities to allow the couples to manage this next phase of the spousal transition.

Managing the relocation to LTC.

Most often the move to LTC was not a planned event, but occurred as a result of a separate physical condition being addressed through a sudden hospital admission. The partners were assessed for LTC placement at that point in time. Caregivers described the experiences as they occurred for themselves, their perceptions of how the experience was for their partners, and how they managed as a couple with relocation to LTC.

One caregiver was anticipating a second relocation for the partner after a year in care. The partner had been paneled for care but due to other physical health concerns the partner remained on a unit waiting placement at a LTC facility. The caregiver was pleased with the current residence and care. The caregiver shared concern about the quality of care that the partner might receive if relocation to another facility were to occur.

The spousal caregiver.

Most of the caregivers' energies had been devoted to supporting themselves and their partners at home. The relocation juncture was exhausting both physically and emotionally for the caregivers. Caregivers attempted to manage their own needs while continuing to attend to the needs of their partners and their needs together as a couple, amidst the unknown territory of relocating to LTC.

Planning for relocation.

At this stage in the spousal transition it became apparent that Home Care and Mental Health Services were available to the couple only while the partner was living at home. One of the caregivers indicated how well these services had provided care when the partner was at home and that their contact with her declined rapidly and ceased once the partner had moved.

Most of the caregivers became immersed in the relocation stage of planning when their partner had been admitted to hospital and the process of paneling for care had commenced. Prior to this time, the caregivers had begun to discuss relocation planning with their families, as well as their doctors and mental health service providers. Choices regarding which LTC facility would be preferred had been explored and considered. Now that their partners would not be returning home from hospital, the caregivers were required to use their strengths to manage these imminent decisions to ensure the comfort of their future as a couple.

Some caregivers relied upon the support of family to assist in the decision making while some caregivers were required to manage these decisions on their own. The paneling process provided the caregivers and their families with additional information and support to assist with making the decisions and coping with the changes as they were occurring. A family conference was beneficial for a caregiver to be able to include family members in decision making.

Some of the couples had benefitted from using the day programs support while their partners were still living at home. Connection with these programs provided some ease for the caregivers within the transition of relocating their partners from home to LTC through familiarity and comfort with the staff and facilities.

A social worker at a LTC facility where one of the partners attended day programming provided support and guidance for a smooth transition from home into LTC. Arrangements were

made to have the partner's room at the LTC facility readied with furniture and personal belongings, right down to having his slippers beside his bed. The partner was taken to this room following day program one afternoon and did not return home. The caregiver appreciated this plan as there had been concern of resistance from involving the partner in planning the move from home to LTC.

One of the couples had used psychiatry and geriatric mental health services to prepare for the relocation to LTC. When the time came for the partner to move from home, due to sudden aggressive and unmanageable behavior, he was required to go to a LTC facility that they had not selected. The LTC facility of their choice was not available at the time and a temporary placement at the assessment unit was not appropriate. The spousal caregiver believed that her partner did not receive the medical follow up required to make continual medication assessments and his care was compromised. The care at this LTC facility was not what the caregiver had wanted for her partner. As a result, the application process for relocating to the facility of their choice was arranged by the caregiver.

Experiencing guilt and grief.

Caregivers shared their experiences of the mixed emotions, of relief, for their partners receiving the care and safety that they needed, and the sorrow, of not being able to have their partners at home with them. Caregivers had previously described the grief they felt at the loss of the social, emotional, and cognitive aspects of their partners. Now the caregivers were experiencing the physical loss of their partners,

"I kept him home as long as I could but I could, couldn't look after him. He needed more care than I could provide..."

and the sorrow that accompanied these changes,

“I felt so badly....she had to go through that...new facility, not knowing anybody...had to sleep by herself...I felt awful.”

The physical transition for this couple was apparent in the empty picture hooks on the walls and the spaces where items had been. These belongings had been passed on to children and grandchildren as the caregiver prepared to move from their marital home to assisted living.

Acceptance, that their partners had permanently moved from their marital home, did not occur for all of the caregivers until well into the paneling process and sometimes not until the move from the hospital to the LTC facility had occurred. Some caregivers described being ready for this point in the transition and welcomed the alleviation of the stress that had been involved in having their partners living at home.

Preparing for the next steps of the transition was easier for some of the caregivers than others. Some of the couples had discussed planning for their physical needs as well as financial futures and had taken care of the particulars. Some of the caregivers were left to manage these decisions and specific paperwork on their own or with the support of family.

Taking on the details of separation.

Issues of legal and financial matters regarding the physical separation of the couple were difficult for some of the caregivers to manage. Sometimes the process was confusing and the agencies involved were not understanding of the couple's predicaments. Some of these issues were frustrating, upsetting, and costly for the caregivers to sort out. One caregiver told of the complications regarding taxes due to the government paperwork, now indicating they were separated,

“...it’s amazing what you can get into that you don’t think about...but I told them over and over again, there is no way he can sign a paper... and it takes so long when you’re dealing with that.”

Family members and the Alzheimer Society had been helpful in assisting and advocating for the caregivers. Some couples had sought guidance with regards to the legalities of changing living arrangements early on in the diagnosis of dementia.

The partner with dementia.

The caregivers shared their senses of their partners’ perspectives regarding the move from home to LTC. Initially most of the partners were dealing with physical health issues upon arrival at the hospital. There may not have been awareness at that point that this move was anything more than for physical health reasons.

Adjusting to new surroundings.

Physical health issues were stabilized and the paneling process proceeded while the partners remained in hospital. While in transition from home to the hospital and waiting to go to LTC, some of the partners had questions of why they were in hospital and when they would return home. Hospital staff helped the caregivers to deal with these questions in manners that were not misleading or upsetting for the partners. Most of the partners adjusted to their hospital stay and cooperated with care and assessment. One of the partners required family or hired sitters to supervise the stay at the hospital. This partner’s confusion and physical ability presented as a potential safety issue for wandering and injury.

Most partners were required to make adjustments at least twice during the transition from home to LTC. Most often a stay in hospital occurred as an interim from home to LTC. One

partner moved from one LTC facility to another which has become a permanent home. One partner moved from home to his new room in LTC in one day.

Still after three months waiting to go to LTC, the partner recognized the facility as a hospital and would occasionally ask the caregiver why he was there and when he would go home. Until the day he was moving to LTC, the caregiver would attempt to sooth her partner with reasons regarding physical health. On the day the partner was told he was moving to LTC, the caregiver saw in him that he understood what was occurring,

“...he just seemed to have sunk down in his chair...you got that impression that he just realized this is, this is it. I won’t go home...”

The caregiver informed that from the day he moved to LTC he did not ask once about where he was or why and seemed to accept this as his new home.

Experiencing the quality of care.

The length of time spent in hospital prior to relocating to LTC averaged 3 months. Most of the caregivers were pleased with the quality of care that they observed for their partners while in hospital. One caregiver expressed concern regarding the care her partner had received while at the hospital. Another hospital resident’s wife had informed the caregiver that the staff yelled at her partner when she was not there and they could have treated him better. The caregiver stated she observed that his hygiene and nutrition were being attended to and she did not investigate the matter of care any further. She was relieved when he moved to LTC as she felt,

“He was a person again.”

The caregivers determined the quality of care their partners were receiving by the way their partners presented and interacted with them when they visited. The caregivers were aware that their partners may not be able to express their experiences and that their expressions may not

be accurate. The caregivers observed their partners to be happy and content and that their partners did not display any indications that there were concerns with the care they were receiving.

The couple.

Acclimating to this major change in the couples' lives was described as the most disrupting period of time throughout the transitions. The couples had been together for many years and not living together was a disconcerting experience.

Trusting the system to provide care.

The caregivers were challenged with allowing the health care system to provide care for their partners. Some of their experiences with the health care system, while still in their homes, provided concern for the caregivers, as they had to relinquish care to another aspect of the system. The caregivers experienced shifts in how they participated in the care that their partners received when they moved to LTC. Some of the caregivers attended regularly to the LTC facilities to assist with feeding and hygiene. Adjustments were made as the trajectory of dementia required care that the caregivers could not provide. Regular attendance to the LTC facility was partly due to the habit of care for their partners and awareness that, with the staffing shortages in the facilities, staff may not provide the care they expected for their partners. A caregiver shared concern that the staffing shortages may never be addressed if the spousal caregivers continued to provide care.

Some of the caregivers were assertive regarding their expectations of care for their partners. Some of the needs were attended to and some of them were not. A repeated request for her partner to be dressed each day in long underwear, both tops and bottoms, was not headed by the staff. Another caregiver requested the use of soft cloths and no soap to prevent irritation of

her partner's skin. The caregiver was aware that her partner walked and had occasion to come into contact with other residents and have his feet run over. The caregiver requested that her partner be dressed each morning with steel toed runners to protect his feet from injury as a result of the motorized wheelchairs. Most of the time these requests for care were not followed.

A partner had received a catheter while in hospital and was transferred to LTC with it remaining in place. After the partner had relocated, a family member advocated for the removal of the catheter in order to promote mobility and appropriate continence care.

Despite the concerns that were shared, the caregivers mostly were pleased with the care that their partners were receiving in LTC. Each of the caregivers managed to enjoy their time with their partners and to address care issues as they arose.

Navigating time together.

Caregivers were able to develop routines for time with their partners. Juggling the tasks and chores, which continued to need to be done in the home, with the hospital visiting hours required planning. As the partners relocated to LTC, the caregivers arranged their couple time around activities and events that were important aspects of their partners' days. Four of the caregivers visited their partners on a regular basis, but not every day. Two of the caregivers visited their partners every afternoon. The caregivers valued the time they spent together but informed that it was exhausting trying to visit every day and maintain their home at the same time. When asked how the caregiver managed with the partner's relocation, the participant responded,

"I guess it's just something you have to accept and, you know, it's life. You have to learn to live with it...as long as you can still go over and be together... a couple of hours a day that's what I think helps"

One of the caregivers relied on handi-transit to be able to visit so this added an additional factor to negotiate in the amount of time the couple had together. A neighbor would sometimes provide transportation but this person was soon moving. The caregiver was planning a move to an assisted living residence and had selected a facility in part because it provided regular and convenient transportation to enable visits to her partner.

The emotional strain was difficult for the couples to handle. The situation was described by a caregiver,

“...being the lowest part of my life...”

and the partner informed one day,

“...us living apart like this is just not right...”

Normalcy had existed when the couples were living together, despite how difficult managing the changes had been. Living apart was described as requiring physical, social, and emotional adjustment.

Adapting to life apart after relocation.

Caregivers spoke with mixed emotions of sorrow and relief at their partners having relocated to LTC. Living in LTC provided safe environments for the partners and peace of mind for the caregivers. With their partners cared for in LTC, caregivers gained opportunities to care for themselves while maintaining relationships with their partners.

The spousal caregiver.

Changes continued when the partners relocated to LTC. Caregivers adapted to the ongoing trajectory of dementia for their partners and changes in care required. The caregivers stated that these changes also affected them as spouses when they spent time together and in assisting with care and decision making.

Self-care.

Support from family members and friends, or professional respite and day programming, had provided blocks of time in which the caregivers had been able to complete errands. Often the caregivers felt rushed and pressured to complete the necessary tasks of shopping and household errands. The most important tasks were completed, sometimes adding to the list for the next week. Seldom had there been enough time for the caregivers to engage in self-care activities in addition to the household responsibilities.

With their partners living in LTC, caregivers were afforded the time to attend to their own self-care. Self-care was a concept somewhat foreign to the caregivers. Some of the caregivers had not engaged in solo activities for leisure and wellness outside of the home. Others enjoyed reading, collecting, and sharing recipes or crafts and hobbies that were done at home. The caregivers continued with these activities while their partners were resting or sleeping. Some activities had been abandoned long ago due to the need for increased time and attention with their partners. Some of the caregivers' interests or abilities had changed and they were left with finding new activities for their leisure and self-care. Some of the activities had been enjoyed with their partner and caregivers adapted to attending on their own or they stopped attending such things as seniors groups. The importance of physical activity was maintained by the caregivers who had shared that with their partners. The opportunity now was available to increase the types and amounts of activities that appealed to the caregivers. One of the caregivers informed of plans to return to line dancing and bridge and was planning a holiday.

Continued care for the partner.

Most of the caregivers continued to provide care for their partners, which they would not have received from the LTC staff. Generally, the caregivers did not have issue with assisting

with care but expressed confusion and frustration with care that was the responsibility of the LTC facility. Some of the caregivers were assertive and advocated strongly for the care of their partner. Others may not have spoken up as much as needed to get answers to their questions and evoke change in their partners' care.

A caregiver described the need for ongoing assistance for her partner's care regarding outside professional appointments. The caregiver was not physically capable of managing her partner in his wheelchair to attend to an optometrist appointment and was required to hire professional help to provide her assistance. An additional concern was the lack of continuity from when the partner had lived with the caregiver to now being cared for in the LTC facility. The caregiver was in the midst of ensuring that the staff members were clear on the medications and appointments required for treating her partner's glaucoma.

A caregiver had issue with what she believed to be the mistreatment of her partner's hearing aids rendering them broken and unusable. This same caregiver had replaced her partner's electric razor twice due to it being broken and lost. As of yet, the caregiver had not shared these concerns with staff members of the LTC facility.

The issue of appropriate dementia care was expressed by a few of the caregivers in regard to LTC staff's language barriers and a lack of understanding the non-verbal nuances of dementia care. A caregiver made a suggestion that LTC staff members who do not speak English well should not be providing care with dementia residents. The caregiver was frustrated with the confusion created for her and she was concerned for the impact upon her partner.

The partner with dementia.

Some of the partners verbalized their approval and pleasure with their new living arrangements. When the partners did not verbalize their experiences, caregivers were able to determine by their actions whether or not they approved and were content.

Settling into a new home.

Caregivers had been concerned that the partners would not settle well into their new environments. The caregivers expressed their pleasure and relief at the fact that their partners were happy and content in the LTC facilities,

“I think he's more at home and happier than he's been since, for years, since the onset of his dementia.”

Once moved to their permanent residence in LTC, the caregivers described that their partners began to experience a sense of their new residence and adjusted well. The partners shared in activities that their spouses were involved in at the LTC facility. One of the partners did not or could not verbalize orientation to surroundings,

“I don't know if he knows why he's in the home...I don't know if he knew it was Christmas.”

Consistent involvement, with other people providing care and exposure to other persons with dementia provided through the day program, was described as helpful in the transition for the partners. None of the partners expressed or displayed displeasure at being at the LTC facility.

Care in the LTC facility.

The partners were provided with safe environments, stimulating activities, and homelike atmospheres. The partners were engaged with other residents and created new homes for

themselves. The partners received care preferences they had received while living at home. One of the partners was able to continue to have her hair done each week at the hairdresser. Another partner was able to continue to enjoy attending church services.

The couple.

At the time of the interviews the couples had experienced on average 13 months of time where the partners had been living in LTC. This amount of time provided them with an understanding of the experiences involved in adapting to life apart as a couple.

Life apart while remaining a couple.

Making decisions regarding health care management choices continued to be a way in which caregivers remained actively involved in their partners' lives and provided them the opportunities to continue to feel as though they remained as couples. They continued interactions with family members and friends as couples. Caregivers reported that changes in their living arrangements did not change the commitment to their relationships as husbands and wives. When asked to describe the experience of living apart, one of the caregivers replied,

"Life is over for us two together...it's just like we're not a couple anymore..."

Another caregiver shared,

"...you can't live with somebody for 63 years and then suddenly be torn apart like that...anyway, I guess that's life."

The caregivers shared the emotional difficulty in their attempts to accept and adapt to the changes as they occurred throughout the trajectory of dementia including now that they were living apart.

Continuing to enjoy activities together.

All caregivers adapted activities to provide for safety and allow the continued dignity for the partners as these transitions were made. The couples participated in many endeavors which were previously enjoyed but were now experienced in ways that suited the changing needs of the partner. Attending curling or rodeo was done as observers now and not as participants. Going out to dinner entailed a catered meal in the common room with neighbors in their building as opposed to going out to a restaurant. The frequency and duration of outings were adjusted to meet the partner's changes in energy and tolerance for these undertakings.

Often these changes in enjoyment of activities involved the understanding and support of the friends and family, to provide accommodations for the partner to continue to be a part of these events. Even prior to relocating to LTC, golfing and curling teammates assisted the partner to be able to continue to be involved in activities with some additional guidance and direction. One couple continued to enjoy a weekly evening out at a local organizational club where their friends accommodated for the changes in the partner's ability to remember and tolerate the activity. These accommodations allowed the couples to enjoy activities together in safe and meaningful ways for both of them.

The LTC facility also provided the couples with the opportunities to enjoy time together. These activities included church services, teas, gatherings, games, and entertainment. Quiet areas were provided where they could be together. One of the caregivers stated that she and her partner did not attend many of the activities available, as she was unable to maneuver her partner's wheelchair around the facility.

Development of intimate relationships.

Two of the caregivers shared their thoughts and feelings regarding situations of their partners and the development of intimate friendships with others while living in LTC. The caregivers were not distraught by these occurrences and both stated that they thought the situation was important to discuss.

One of the caregivers stated that she walked into the LTC facility to find her husband sitting asleep on the dayroom couch holding hands with a female resident. The caregiver was initially shocked and saddened. The caregiver described being able to quickly compose herself and accept her feelings and not let them interfere with her visit with her husband. After a few moments she was able to approach her husband and gently wake him. Her partner was pleased to see her and was unaware of there being anything happening that was unusual. The caregiver understood that this may occur with dementia.

Another caregiver shared that during an afternoon visit her partner informed her that he had a girlfriend. The caregiver acknowledged her partner's statement and did not elaborate or ask questions. The caregiver believed that the partner would soon forget having said it and knew not to make too much of the statement. The caregiver and the partner's son were able to discuss the situation as a matter of occurrence within dementia.

These caregivers described themselves as being pragmatic and open minded, allowing for their ability to understand and accept the situations. They shared their experiences with their children and their spouse's children. The caregivers wanted the discussion to be out in the open and as comfortable as possible for themselves, their partners, and all family members. These situations had occurred since the first interview and there had not been much discussion with family members at the time of the second interview. Neither of the caregivers had concerns

regarding the management of the situations. There had not been discussions with the LTC facility staff at that point as to their awareness and acceptance of the situation.

Using this knowledge to enhance practice and policy

Themes were developed to better understand the experiences of spousal transition within dementia and relocation to LTC. From these themes, the next steps are to pose considerations for adaptations in support services/programs, as well as practice and policy changes required to assist the needs of the caregivers, the partners, and the couple units throughout the transitional phases of relocation of the partner to LTC.

How can the health care system support couples to manage together in their own homes, ease the burden as partners relocate to LTC, and support the couples' relationships as they adapt to living apart? How can awareness and education be provided for family members and friends, to best support couples to live safely in their own homes and assist them with the transitions to LTC as changing needs occur? What practice and policy changes are required for health care workers to provide care and support for caregivers and their partners to manage in their own homes, as the partners relocate to LTC, and as the couples adjust to living apart?

The experiences of the couples in this study were the basis for the development of themes. The discussion section will be used to review the themes and present potential applications of care and support for couples.

Chapter 5 - Discussion

Thematic analysis and discussion of the participants' experiences will be disseminated to health care professionals with the goal of improving their understanding of the needs of these couples and aiding in the further development of supports for the couple as the unit of care. The value of this research has been the creation of a window into the caregivers' interpersonal beliefs, coping skills, supports, and knowledge of dementia related to their own needs, their partners' needs, and their needs as couples. These needs were shown to change throughout the phases of transition, while the couples were living together, moving apart, and adjusting to their new lives as couples with partners residing in LTC.

This research study was conducted with a focus on couples' strengths embedded within the experience of the partners living with dementia relocating to LTC. The goals of this study are to support improved care provision through clinical practice and policy evolution. The strengths and limitations of the study are presented along with suggestions for further research.

Managing the Lived Experience of Transition

The most significant findings from this study are issues surrounding spousal caregivers seeking and maintaining appropriate health care services which would allow the couples to continue living together for as long as they chose, having a smooth relocation process, and sustaining a couple relationship as they adjust to living apart. The issues were described as having occurred to varying degrees within a variety of needs during different stages of the trajectory of dementia for each of the couples. The caregiver's perspective of the needs of the couple is viewed as an expert viewpoint into the development of appropriate services.

Knowledge based on the couple as the unit of care, while simultaneously considering the needs of the caregiver, the partner, and the couple throughout the phases of transition will be used to

inform health care programming and policy with the goal of providing quality and continuity of care for couples. How persons experience illness depends on the beliefs that they have embraced prior to the illness experience, as well as the beliefs that evolve throughout the experience of the illness (Wright, Watson, & Bell, 1996).

Living together.

The couples' needs related to the trajectory of dementia required them to make choices and changes to accommodate living together. Couples' abilities and strengths provided them with a foundation for coping with the struggles related to dementia. The deteriorating cognitive, behavioral, and social functioning of the partner with dementia led to increased care related to daily needs and safety issues. Caregivers' frailty and health issues both impacted and were impacted by the increased requirements in daily care for their partners. Recommendations for services and supports are linked to findings from the study. Appropriate, consistent, and timely services are needed to assist caregivers with daily care for their partners, while managing their own health needs, and supporting the couple through the spousal transition within dementia.

Caregiving.

Couples' abilities and strengths, cultivated over time within their relationships, helped them to manage the changes associated with dementia. The couples' intimate and long term knowledge of each other provided them with advantages in navigating the functional changes of dementia. Building upon routine and consistency, as well patience and tolerance, contributed to the successful management of changes in care for the partner.

Some caregivers' health issues created a need for temporary additional supports while they were recovering or receiving treatments. For other caregivers, frailty and declining physical strength warranted supports to assist with managing daily care for themselves and their partners.

Without the support of their partners, caregivers were required to handle the couples' needs. The caregivers developed their support networks to include family and friends, in addition to the health care system. The data collected from these participants can be used to provide health care professionals with additional awareness of couples' needs and abilities to support one another.

Services and supports.

The participants in this study confirmed their family doctor as the first person to assess their partners with possible dementia. The elderly population continues to use physicians as a point of entry to the health care system (Van Hout, Vernooij-Dassen, Jansen, & Stalman, 2006). A definitive diagnosis of dementia may take three months to a year (Gibson & Anderson, 2011). Therefore, ongoing supportive assessment and referral to allied health care services are important aspects of assisting couples during the diagnostic process and throughout the trajectory of dementia. Cognitive screening at regular intervals during appointments with health care providers, informing both spouses of the results, and making appropriate referrals are key strategies in providing care for couples with dementia (Brown & Chen, 2008).

Community services were available for the couples through in-home supports, respite care, and transportation services. Personal support networks also played an important role in the quality of life for couples as they transitioned through the phases of dementia.

In-home supports.

The Alzheimer Society plays a valuable role in providing education and support programs for couples as they maintain the independence of living in their own homes. Home Care case coordinators could provide more holistic management of services by viewing the couple as the unit of care. Nursing staff's assessment of the couple as the unit of care should explore the caregiver's needs, the partner's needs, and the needs as they relate to the couple.

Input from the participants is important in order to provide appropriate care. Nursing assessments should be used to provide direction for support staff to assist couples' independence and interdependence.

In-home support staff require dementia care education and must be committed to meet the caregivers' and partners' needs through skills to provide care and compassion. In-home support staff should engage caregivers' knowledge of their partners' needs for mobility and hygiene, and assist with the physical and cognitive demands in the changing needs for care. Quality of life is greatly improved when the personality and interests of the partner can be included in the daily support and care routine.

The use of the same members of the Home Care staff, attending at consistently scheduled times would create familiarity for both the couple and the staff, providing for continuity of care. Safety issues associated with falls, aggressive behavior, confusion, and wandering should be managed through ongoing assessment of daily functioning. Home Care service providers require the skills and resources necessary to assist with mobility issues that involve changes in the couples' physical abilities. Changes must be assessed continuously and adaptations made as required to meet the couples' unique and specific needs for care. Services must be adapted to meet the needs of the clients, as opposed to clients adapting to the services.

Respite care.

Additional and alternative respite care is required to meet the specific needs of couples. Caregivers need to take care of tasks and errands, as well as attend to personal health and self-care. Respite care needs to be flexible in terms of the amount of time and the location where respite services are provided, to best suit the needs of the couple. Respite care should be provided in a manner to allow the caregiver with the opportunity to remain at home while the

partner is escorted to attend activities of interest. Caregivers must be provided with sufficient time for respite so that they are able to attend appointments and manage their self-care.

Overnight respite care should be more readily available to assist a couple when the partner is not sleeping at night. Day program services also need to be more tailored to meet the differing and unique care and respite needs of the couples. Varying times for attendance, alternative activities, and opportunity for spouses or family members to participate in events as they desire, would be beneficial for couples.

Access to transportation.

Some participants expressed concern that their partners' dementia symptoms impacted their abilities to safely drive a motor vehicle. Dementia impairs insight and judgement and may lead to relational discord around the issue of driving. Physicians need to cooperate with couples to intervene when the caregiver recognizes these safety issues. Candrive (2015) is a program which helps to ensure elderly at-risk drivers are safe drivers in accordance with the Canadian Medical Association (CMA) through reporting requirements associated with the provincial Ministry of Transportation legislation.

The interim time period from physician assessment of driving safety to receipt of the official letter of driving restriction created stress for one couple. The caregiver struggled to avoid the need for her partner to drive during this time. Couples experience difficulties and loss of their independence when the sole driver's license had belonged to the partner with dementia.

Access to appropriate, affordable, and convenient transportation is necessary for these couples as they adapt to the changes associated with dementia, while remaining in their own homes. Transit must be available to assist those persons with limited mobility from door to door and be available at the times when they are needed.

Personal support networks.

Development of personal and professional support systems can be effectively planned with increased understanding of the obstacles and challenges experienced by these couples. The participants reported changes in relationships with family and friends. Contact with family and friends changed in regards to frequency and amount of time for visits, as well as the level of ease of interaction in association with the symptoms of dementia. Early assessment of personal supports will strengthen the connections with these supports to enhance the couples' resilience and capacity to manage in their own homes. The Alzheimer Society provides information to help family members and friends to understand the shifting social and behavioral changes and to be able to provide appropriate, beneficial support. When family and friends know how to manage the symptoms of dementia, such as confusion, agitation, and wandering, they will be better equipped to support the couple living with the changes as they occur.

Engagement of family and friends, who now understand the symptoms of dementia, will reduce caregiver isolation and hopelessness. The challenges, of limited knowledge of dementia and the presence of stigma regarding mental health, increases stress and interferes with caregivers receiving care and support from family and friends as well as within the health care system.

Dementia Friends Canada (Alzheimer Society, 2015) is a new public awareness resource used to provide education, address stigma, and support the care of persons with dementia. The Dementia Friends Canada campaign extends to the internet and social media as a major avenue for the dissemination of educational and supportive material. This information is used to address stigma and identify supports for living with the disease. The elderly population is beginning to use the internet and social media, and this use will increase with the younger populations. Still,

the older generations require additional ways to receive the information available online regarding symptoms of dementia and the availability of services and supports.

Community health care providers can be valuable resources in assisting couples, with the transfer of care from home to hospital units designed for temporary care provision, as well as in the direct relocation to LTC. Knowledge of the trajectory of illness, resources available, and ways to link to these services are required by caregivers. Spousal caregivers remain the best source of knowledge regarding the needs of the couple. Caregivers should be encouraged to inform health care providers in LTC facilities of ways that they can support the couple and each of the partners through the transition of relocation to LTC.

Relocating to LTC.

Frequently, the need for relocation occurred unexpectedly and quickly as a result of physical health issues, often related to dementia. Support of and guidance during the earlier stages of transition were effective in decreasing the burden for the caregivers and stress for the partners, as well as assisting with the grief and loss experienced by the couples.

When the couple is viewed as the unit of care, caregivers would continue to benefit from previously existing Home Care and Mental Health Services during and after their partner relocated from the marital home to LTC. Effective health care providers support caregivers with understanding and assisting their coping with guilt and grief while they adjust to the relocation and their partners adjust to their new surroundings (McGovern, 2011). Continued assistance at this critical point of transition would provide a bridging support for the caregiver who is left in the home.

Assertive advocacy is an important skill for caregivers at all stages of transition and especially when they become more reliant upon the health care system for their partners' care.

Caregiving spouses know their partners' care needs for mobility, physical and emotional comfort, nutrition, and elimination. Transfer of this knowledge, from the caregivers to the health care professionals, requires open communication and respect for spousal caregivers' expertise and adaptation of that knowledge into the treatment plans for the partners who are coming into care (Hyden, 2013).

Legal and financial issues created frustration and stress for the caregivers during the time of relocation. The Alzheimer Society First Link program (2015) provides support and education to the person with dementia and his or her caregivers. Information for planning is current and is focused on the best interests of the caregivers, their partners, and the couple units. Important topics are future care needs and the changes associated with the trajectory of dementia, such as health care directives and end of life care, as well as the transitions within dementia care involving financial and legal matters. A holistic approach to care may reduce stress and crisis, prevent unplanned visits to medical care facilities, and assist with relocation planning and adjustment.

The couple's union has been altered by physical relocation of the partner to LTC. Couple relationships continue to exist and require empathy of the health professionals. Gleaning information from these spousal caregivers will provide health care staff with knowledge and understanding to encourage and support couples in navigating the relocation and in managing their lives together while living apart.

Being apart.

Spousal caregivers continue to provide care for their partners after their partners have relocated to LTC. The opportunity for LTC staff to engage with and support husbands and wives in the mutual care of their partners may be accomplished through shifts in practice. LTC staff

must follow through on daily care requests from the caregivers for their partners. The sensory needs of partners with dementia can be met through accurate nursing assessment and care. Respect must be shown for personal belongings, such as hearing aids, razors, and dentures through ensuring that equipment is well-maintained and appropriately stored.

Caregivers expressed concern for LTC staff's language barriers and lack of dementia care knowledge. LTC management teams must ensure appropriate education, training, and supervision for the staff to deliver quality care. Communication is crucial in effective care for persons with dementia. Hearing and cognitive deficits of the partners must not be complicated by limited or difficult use of the first language of the partner. Health care providers must be effective communicators.

LTC staff should provide care and support for elderly and frail spouses as they continue to be involved in care for their partners. Ongoing assessment of care needs for the couple will allow spouses to remain involved in their partners' care, but not be responsible for their care (Nolan, Davies, Brown, Keady, & Nolan, 2004). Spousal caregivers should be able to rely upon LTC staff to adhere to their partner's treatment plans without having to follow up on the care provision. The partners and spouses may need assistance to attend medical appointments outside of the LTC facility. LTC facilities should have services and resources to support attendance at such appointments. LTC staff may assist couples to enjoy activities together by assisting with moving wheelchairs to events or providing private space for them to have time together.

Development of intimate relationships by partners with dementia, with other residents, is a specific area of concern following relocation to LTC. In accordance with Bauer, Nay, Tarzia, Fetherstonhaugh, Wellman, and Beattie (2014), the topic of residents' sexuality must be undertaken as an important aspect of supporting couples relationships while they live apart.

Discussions with management and staff will allow for further exploration of the most appropriate ways to assist with this delicate matter of dementia care with respect for each couple's wishes.

Couples' relationships continue to exist when they no longer reside together in the same home. Their lives apart require a certain understanding of the experience of spousal transition and the importance of their desire to maintain their relationships.

Policy Evolution

The Alzheimer Society of Canada (2010) commissioned a study on the impact of dementia on Canadian society. The Rising Tide study includes existing and emerging policy responses in other countries and parts of Canada, which are directed at increasing the integration of health and social policies, establishing more home-based programming, and adapting LTC facilities to better meet the needs of residents. Education programs for people with dementia, their families, the public, and health professionals are further developed through the knowledge gained as a result of research. This research study is supported through funding from the Alzheimer Society of Canada. The goal of the study is in keeping with the recommendations from that report and the findings will be useful to improve services and supports for couples.

The Alzheimer Society of Canada fundraises for a cure for dementia. The emphasis is on cure with less regard for care and the programming component to support quality of life for people affected by dementia. The language in promotional advertisements needs to be expanded to raise awareness of the value of care and programs for people living with dementia and their caregivers.

Health care professionals work toward improving assessment and coordination of care for persons with dementia and their caregivers. The purpose of health policy is to guide clinical practice and patient care (Oxman, Lavin, Lewis, & Fretheim, 2009). Policies which are

informed by evidence, shape the best practice guidelines. Policy plans are implemented through collaborations between government agencies, legislators, residential care providers, community care providers, people with dementia, family members, physicians, and researchers.

The Caregiver Policy Lens (MacCourt & Krawzick, 2015) is a tool used for the development of policy, legislation, programs, and services that support caregivers.

Recommendations for policy evolution are created with caregiver inclusion and voice, consider collaboration of services, and follow a sound evidence-informed evaluation.

Viewing the couple as the unit of care would provide the opportunity for health care providers to develop files to include both members of the couple, while working within the parameters of the Personal Health Information Act (Government of Manitoba, 1997) and the Mental Health Act (Government of Manitoba, 1998). The recommendations from this study for synthesized care are supported by the Canadian Home Care Association (2012) and the Mental Health Commission of Canada (2012).

The needs of the caregivers, their partners, and the couples would be managed interrelatedly while they are living together, during relocation to LTC, and as they live separately. Adjustments in care policies with consideration of their interrelated needs may provide couples with more choice in how they endure the changes associated with dementia. Beginning with assessment and diagnosis through the stages of care planning, a couple file would lead to effective care that supports the strengths and abilities of the couples to manage with appropriate assistance.

Respite care policies must be responsive to the unique needs of each couple. Increased service time allotted at varying times of the day and night would better serve the needs of couples. Supporting these respite needs will increase couples' opportunities to manage their care

together in their own homes, providing them with more choices in their transitions. Policy should allow for respite services to be provided in the home as well as outside of the home. Respite services that take individual clients to events and activities in the community help keep the clients connected with the community. Day care programming policies must provide flexibility for couples to use these services to best suit their needs. Variability in attendance times and choice in activities would improve the quality of care within this service.

Alzheimer's Disease International (2015) stated that the key to winning the fight against dementia lies in a unique association of global solutions and local knowledge. As such, shifts in policy work locally, by empowering national Alzheimer associations to promote and offer care and support for people with dementia and their caregivers, whilst working globally to focus attention on the epidemic and campaign for policy change from governments and the World Health Organization. The Canadian Medical Association (2013) supports increased investment in research on key aspects of dementia; including prevention, treatment options, and improving quality of life, as well as increased support for informal caregivers. The Alzheimer Society could further the development of the family education series through exploring additional methods of meeting couples' needs, specifically as they move through relocation of the partner to LTC and adaption to living apart.

Strengths and Limitations of this Study

Gaining a deeper understanding of couples' experiences of the physical relocation of the partner with dementia as a transition will enable health care professionals to provide better assistance to caregivers. Phenomenological inquiry is consistent with nursing science in seeking to understand individual persons rather than groups of people and then taking this knowledge

into the next encounter of practice (Rolfe, 2006). Phenomenological research involves the investigator within the dialogue and discovery of the lived experience.

The participants were educated, culturally and socially connected, displayed effective personal health choices and coping skills, were financially stable, and independent in their own daily care. The determinants of health experienced by these participants generally would allow them opportunity to access health care, which may not be the case for couples.

Although only 7 participants were involved in the study, much useful data were gathered. However, several more women than men were interviewed so the information is more transferable to women and additional key information may be gathered in additional interviews with men. The participants all lived in the same city which may limit the transferability of the needs expressed as other locations may provide alternative services and supports.

The findings from this study will be used to contribute to the current literature informing health care practice supporting the lived experience of couples before, during, and after relocation of the partner with dementia to LTC. The application of this knowledge and recommendations within multiagency and interdisciplinary fields will increase the effectiveness and proficiency of the health care system and better serve the needs of the couples.

Directions for Further Research

Researchers seek to gather understanding and awareness of a phenomenon and then use this knowledge to create further questions. This study was used to provide caregivers with the opportunity to share their experiences of the physical and tangible needs of the caregiver, the partner with dementia, and the couple unit. A longitudinal study would be useful to explore deeper understanding of the emotional, social, and spiritual aspects of transition for spousal couples over time. Conducting the research while the transition is occurring rather than as a

retrospective study, could increase the accuracy related to memory, and also improve the detail that participants were able to provide. Phenomenological study regarding sexual expression with non-marital partners within the residential aged care environment would contribute to the increasing body of literature on this topic. Research into end of life care would provide information on another transition experienced by these couples as they live through the final stages of dementia.

Chapter 6 - Conclusion

Life's transitions can be seen through two great developmental shifts (Bridges, 2004). The first involves an end to old dependencies and the establishment of the person as a separate social entity. The second involves movement beyond that separateness to something more complex, to a deeper sense of interrelatedness (Bridges, 2004). The nature of life in transition as constantly shifting is supported by Rogers' (1970) theory of nursing and hermeneutic phenomenological research is an effective method for seeking deeper understanding (van Manen, 1997) of this experience. Psychiatric nurses strive to engage, understand, and support people as individuals, as well as within their relationships as they move through the experiences of their lives.

Theory and practice are locked in an inseparable whole, such that reflective practice generates informal theory, and reflexive theory modifies and advances practice. This blending of theory and practice has come to be known as *praxis* (Rolfe, 1993). This nursing research project was created using the philosophical assumptions of Rogers' (1970) *Science of Unitary Human Beings*. Rogers was one of the first nursing theorists to identify people as the central phenomenon of interest to nursing. Rogers' assumptions include: a human being is considered as whole and cannot be viewed as subparts; the life process of a human is irreducible and unidirectional; health and illness are continuous expression of the life process; the energy flows freely between the individual and the environment; human beings possess the ability to think, imagine, sense, and feel; humans use language for expression; and human beings have the ability to adapt according to the changes in the environment.

Environmental changes involved with the trajectory of dementia, as well as transitions in the couple's relationships and relocation, are in keeping with the assumptions of Rogers' theory.

The *Science of Unitary Human Beings* has been incorporated throughout this study to ensure that the caregiver and the spouse are seen as individuals. Also, the couple is seen as the unit of care, as unitary in the relationship and related experiences. The assumptions of Rogers inform the exploration of practice and policy evolution in relation to the findings.

A hermeneutic approach in psychiatric nursing is a reflective way to develop an understanding of the deeper meaning of people's experiences by using intuition and empathy to empower people and create a foundation for change and improvement (Holm & Severinsson, 2011). Nursing practice is determining the right thing to do in each particular case, rather than doing the thing that works most often in most situations (Rolfe, 2006).

Van Manen's research methodology (1997) is used in conjunction with these nursing philosophies, which have been used to create a foundation for this study. The findings from this research study will be shared with spouses, families, and health care professionals, who support individuals and couples living with dementia. The knowledge gathered from the participants' experiences may enlighten future caregiving and health care practice through appropriate supports and services which are guided by effective policy.

The capacity of the human spirit to find meaning and purpose in life is remarkable and need not be linked with a particular religion or spiritual expression (Stuckey, 2003). The synergism, between the expertise of the spousal caregiver about the experience of living with dementia, and the expertise of the clinician, about managing dementia, will inform the provision of therapeutic support for the caregiver, the partner with dementia, and the couple as a unit (Wright, Watson, & Bell, 1996). The couple's core beliefs should be distinguished through a respectful, curious, nonoppressive, and compassionate relationship between the spousal caregiver and the clinician.

Successful aging is the primary goal of the couple and the individual partners as well. Successful aging involves promoting, maintaining, and managing: 1) couplehood and individual physical health; 2) mental capacity and well-being; 3) engagement with others and with life, and 4) positive spirit, attitude, and outlook or desire to thrive (Melillo, 2005). These goals are met through appropriate and effective public education, care provision, programs, and policy.

Spousal caregivers benefited from sharing their experiences. Supporting the empowerment of participants and advocating for their needs are priorities within psychiatric nursing. When health professionals are better equipped to understand and interpret couples' needs, their abilities to assist couples in living with dementia in the community, through relocation, and in LTC will be enhanced (Robinson, Clare, & Evans, 2005). Health care provider's knowledge about caregiving spouse's experiences, of living with dementia and placement of a partner in care, can assist the caregiver to identify loss, normalize stress and confusion, clarify the effect of memory loss on behavior, and support the reconstruction of spousal roles and relationships (Blieszner, Roberto, Wilcox, Barham, & Winston, 2007). Knowledge of the phases of change within the couple's relationship is useful in maintaining reciprocity, affection, and appreciation (Hellstrom, Nolan, & Lundh, 2007). The experiential stories that were gathered will be useful in assisting in the development of programs and services better tailored to meet the needs of older couples who are living with dementia.

The challenge exists in developing methods to facilitate access of health care team members to the information shared from this study. The creation of a handout detailing the experiences and needs of the couples during the stages of transition will be the first step in the dissemination of the information from this research study. A report of the findings will be shared with LTC facility coordinators, the waiting placement social worker, the Alzheimer

Society program manager, and the Home Care case managers. Coordinators will be encouraged to share the handout with front line staff in order to develop awareness of practice and open opportunities for growth and improvement in supports and services to meet the needs of couples. Agencies will be encouraged to share the handout with spousal caregivers to promote self-advocacy for the assistance required to meet their needs. Family members would also benefit from this handout in order to enhance awareness and understanding of couples' needs.

In examining disease, we gain wisdom about anatomy, physiology, and biology. In examining the person with disease, we gain wisdom about life (Sacks, 1998). The process of research and practice is circular and unending. Applied research is used to gather evidence from which practice can be developed to enhance the care provided within the health care system. This study is a continuation from previous studies exploring the experiences and needs of couples through aging, in particular living with dementia. Researchers must continue in their efforts to understand the lived experiences of couples in order to support their quality of life as they transition through their life stages.

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APPENDIX A

LETTER OF INVITATION

Dear Sir or Madam,

You are being invited to participate in a study to explore transition of the couple, when a partner with dementia relocates to long term care. Developing an increased awareness of this experience will assist health care professionals to better meet the health care needs of these couples and the partners, as individuals, throughout the transition to long term care.

I am a student in the Master of Psychiatric Nursing Program through the Faculty of Health Studies at Brandon University. My supervisor is Dr. Fran Racher. I have been granted an Alzheimer Society of Manitoba Graduate Student Fellowship Award for use in conducting this project. The information gathered will be shared with Prairie Mountain Health and the Alzheimer Society, as well as published in my Thesis. This information may be used in the planning of services and programs that will aid couples, when one of the spouses has been diagnosed with dementia and the couple is experiencing the transition of having one of the partners move into long term care.

At a time and place convenient to you, I would like to meet with you to talk about your experience of the transition from having your spouse reside with you to moving into long term care. Our visit will be about one and a half hours long. A second visit, likely about an hour long, will be arranged to discuss my understandings from the initial interview and to gather any other information that you would like to share. The interviews will be audio recorded and then transcribed. Your confidentiality will be maintained through the use of a pseudonym and your participation will be kept confidential. Participation is voluntary and you may refuse to answer any question or withdraw from the study at any time. Participation in this study will not affect any services that you may be using now or may require in the future.

If you are interested and willing to consider participating, you may give your name and phone number to the coordinator who has given this letter to you or you may contact me directly at (204)724-3873. I will contact you by phone to arrange a meeting to further describe the project to you. I will ask you to complete a formal consent prior to the first interview and review consent upon return for the second interview.

Should you have any questions about participating in the study, please contact me directly to further discuss this project. I may be reached at (204) 724-3873. Should you wish to speak with my supervisor, Dr. Fran Racher is available by phone (204) 727-7414.

Sincerely,

Terri Miller, RPN
Master of Psychiatric Nursing Student,
Faculty of Health Studies
Brandon University

APPENDIX B

CONSENT FORM

Exploring Spousal Transition within Dementia and Relocation to Long Term Care.

This consent form, a copy of which has been given to you, is only part of the process of informed consent. It should give you a basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please feel free to ask. Please take time to read this carefully and to understand any accompanying information.

The goal of this study is to learn about the experience of couples through the transition, when one of the spouses has been diagnosed with dementia and now resides in long term care. Participation in this study will provide spousal caregivers' with the opportunity to share their stories of the transition to long term care. The information gathered will be shared with Prairie Mountain Health and the Alzheimer Society, as well as through my thesis and related articles and conferences. This information may be used in the planning of services and programs that will aid couples, when one of the spouses has been diagnosed with dementia and the couple is experiencing the transition of having one of the partners move into long term care.

I would like to meet twice. The initial meeting will be about one and a half hours long and we will discuss your experiences with the transition. The second meeting will be used to discuss and ensure my understanding of your experience as you had previously described it. At the second visit you are welcome to add any other or new information. I anticipate the second visit will be about an hour long. Audio recording of the conversations will allow me to transfer our dialogue into notes.

The computer files and transcripts of our conversations will be kept confidential and accessed only by me, Terri Miller, my supervisor, Dr. Fran Racher, and the transcriber. The computer files will be saved on a flashdrive and stored with the notes in a locked filing cabinet. In the notes and computer files I will use pseudonyms or false names for

participants. I may quote your words to illustrate a point, but I will never use your name or information that could identify you.

Your participation is completely voluntary and you may refuse to answer any question or withdraw from the study at any time. Your participation will not affect any health service that you may be using now or in the future. Any discovery of abuse of persons in care will be reported to authorities as required by law. You will not incur any financial costs in participating in this research. If you suffer injury as a result of participating in this research, no compensation will be provided for you by the Brandon University, the researcher, or the supervisor of this project. Nothing said here about treatment or compensation alters your right to recover damages. This project is supported by an Alzheimer Society of Manitoba Graduate Student Fellowship Award.

Your signature on this form indicates that you have understood the information regarding participation in the research project and have agreed to participate. This does not waive your legal rights nor release the researcher or the involved institution from their legal and professional responsibilities. Your continued participation should be as informed as your initial consent, so feel free to ask for clarification or new information at any time.

If you have any questions concerning your participation you may contact me directly at (204) 724-3873. You may also contact my supervisor, Dr. Fran Racher at (204) 727-4714 and/or the Brandon University Research Ethics Committee Chair at (204) 727-9712.

Signature, participant

Date

Signature, researcher

Date

APPENDIX C

INTERVIEW GUIDE

Exploring spousal transition within Alzheimer's type dementia and relocation to long term care.

[This guide is a suggested format, to be used with consistency when appropriate. This qualitative approach relies on the premise of adjustment and flexibility in data collection based on the information gathered. Therefore adaptation of the interview format is anticipated and appropriate.]

Personal history

I would like to talk with you about your experiences as a care partner in living with your spouse having been diagnosed with Alzheimer's disease. To begin, I would like to get to know you better as a couple by learning about your lives together.

Please tell me your age and the age of your spouse.

How long have you and your spouse been married to each other?

How did you come to know one another?

How would describe yourselves as a couple?

Where did you live? And work?

Briefly, please tell about family and supports.

Transition

I would like to learn from you regarding your transition through your spouse's diagnosis of Alzheimer's type dementia. From your perspective as a care partner within your relationship as a couple, I would like to understand the transition from living together to your spouse now residing in long term care.

How long has your spouse been in long term care?

Please describe how you have managed with your spouse moving into long term care.

Please describe how you have managed the changing needs as a care partner through the transition to long term care.

Please describe your experiences as a couple through the transition of living together to your spouse relocating to long term care.

What were your experiences that led to the decision to seek long term care for your spouse?

What supported your decisions?

What hindered your decisions?

APPENDIX D



**Brandon University
Research Ethics
Committee**

Research Office
Room 113, Clark Hall
phone 204-727-9712
fax 204-728-7340
burec@brandonu.ca

270-18th Street
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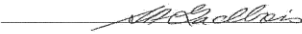
**Brandon University Research Ethics Committee
(BUREC)
For Research Involving Human Participants**

ETHICS CERTIFICATE

The following ethics proposal has been approved by the BUREC. **The approval is valid for up to five (5) years from the date approved, pending receipt of Annual Progress Reports.** As per *BUREC Policies and Procedures*, section 6.0, "At a minimum, continuing ethics research review shall consist of an Annual Report for multi-year projects and a Final Report at the end of all projects... Failure to fulfill the continuing research ethics review requirements is considered an act of non-compliance and may result in the suspension of active ethics certification; refusal to review and approval any new research ethics submissions, and/or others as outlined in Section 10.0".

Any changes made to the protocol should be reported to the BUREC prior to implementation. See *BUREC Policies and Procedures* for more details.

As per *BUREC Policies and Procedures*, section 10.0, "Brandon University requires that all faculty members, staff, and students adhere to the *BUREC Policies and Procedures*. The University considers non-compliance and the inappropriate treatment of human participants to be a serious offence, subject to penalties, including, but not limited to, formal written documentation including permanently in one's personnel file, suspension of ethics certification, withdrawal of privileges to conduct research involving humans, and/or disciplinary action."

Name of Principal Investigator:	Ms Terri Miller
Title of Project:	Exploring Spousal Transition within Dementia and Relocation to Long Term Care
Co-investigator(s):	n/a
Faculty Supervisor: (if applicable)	Dr. Fran Racher Faculty of Health Studies (Psychiatric Nursing)
Research Office File #:	21611 (2014)
Date of Approval:	October 13, 2014
Ethics Expiry Date:	October 13, 2015
Authorizing Signature:	 Dr. Shannon Gadbois Co-Chair Brandon University Research Ethics Committee

APPENDIX E



BRANDON

PMH Ethics Research Committee
Prairie Mountain Health
Regional Administration
150A-7th Street
Brandon, MB R7A 7M2
Phone: 204-578-2305

12 November 2014

Ms. Terri Miller
183 Glendale Bay
Brandon, MB R7C 1E2

Dear Ms. Miller,

STUDY TITLE: Exploring Spousal Transition within Dementia and Relocation to Long Term Care

This is to inform you that the Prairie Mountain Health (PMH) Ethics Research Committee has reviewed and approved the protocol and consent form for the above-mentioned study for **one year**. Therefore the Committee has approved this study to be conducted within the PMH region. The ethics approval for this study is valid until **13 November 2015**.

PMH Ethics Research Committee works under the guidelines of the Tri-Council Policy Statement 2 (TCPS2) and in compliance with the International Conference on Harmonization (ICH E6) and the Canadian Good Clinical Practice guidelines as per Health Canada regulations.

The TCPS2 requires you to notify the Ethics Research Committee of any new advertisements or recruiting material, change of investigator or site location within the PMH region, serious adverse events, amendments or changes in the protocol, significant protocol deviations and/or termination of the study. Please note that you must submit all protocol and informed consent form amendments and /or advertisements including patient brochures to the Committee for review, and await a response from the Ethics Research Committee, prior to implementing the amendments and/or advertisements. Submit annual report for review and approval 4 weeks or earlier prior to expiry date.

The PMH Ethics Research Committee requires that any ongoing information shared with Brandon University must be submitted to the Committee.

The PMH Ethics Research Committee also wanted to share additional comments regarding your research project:

1. The process to approach Long Term Care facilities is unclear. How would Facility Coordinators choose potential participants?
2. The Ethics Committee would appreciate a brief summary when project is complete.

Sincerely,

Denise Logeot, BSW, RSW
Chairperson of the Ethics Committee
Prairie Mountain Health

cc: Dr. S. Gauthier

APPENDIX F

TIME LINE

Exploring spousal transition with dementia and relocation to long term care.

Activity	2014	2015	2016
Contact seniors coordinators	Nov		
Phone participants	Dec	Jan	
Conduct initial interviews	Dec	Jan	
Analyze 1 st interviews		Jan Feb	
Conduct 2 nd interviews		Feb Mar	
Analyze 2 nd interviews		Mar Apr	
Analysis of field notes	Dec	Jan Feb Mar Apr May	
Write thesis			Jun – Oct
Submit to advisor			Nov
Submit to committee			Dec
Oral defense			Jan
Review and revision			Jan
Disseminate research			Feb

APPENDIX G

Brandon University
Confidentiality Agreement

Exploring Spousal Transition within Dementia and Relocation to Long Term Care.

I, _____ affirm that I will not disclose or make known any matter or thing related to the participants that comes to my knowledge during this research project.

Transcriptionist

Date

Signature of Witness

Date