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Molloy College

Barbara H. Hagan School of Nursing

Ph.D in Nursing Program

THE LIVED EXPERIENCE OF RELATIONSHIP TRANSITION IN SIGNIFICANT OTHERS
CARING FOR A PARTNER WITH YOUNGER ONSET DEMENTIA

A Dissertation

by

DIANE PEYSER

Submitted in partial fulfillment of the requirements

For the degree of

Doctor of Philosophy

April 12, 2017

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Molloy College

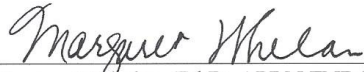
Barbara H. Hagan School of Nursing

The Dissertation of DIANE PEYSER entitled: THE LIVED EXPERIENCE OF
RELATIONSHIP TRANSITION IN SIGNIFICANT OTHERS CARING FOR A PARTNER
WITH YOUNGER ONSET DEMENTIA

In partial fulfillment of the requirement for the degree of

Doctor of Philosophy

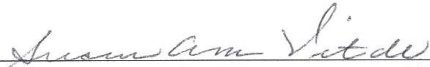
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Abstract

Background

Approximately 5% of dementia sufferers are individuals younger than age 65. The majority of studies have focused on individuals with late-onset dementia. The limited studies conducted on caregivers of younger onset dementia individuals identify that they have a different set of needs based upon their unique experiences. Significant others such as spouses frequently fulfill the role of caregiver for a partner with younger onset dementia. Little is known about the lived experience of significant others caring for a partner with younger onset dementia in the context of relationship transition that occurs in this dynamic situation. This study illustrates the lived experience of that relationship transition as significant others care for a partner with younger onset dementia.

Purpose

The purpose of this study was to explore and highlight the issues of concern for significant others caring for a partner with younger onset dementia, and discover the meanings significant others ascribe to the transition in their relationships.

Method

A qualitative method and a phenomenological design were used to conduct this study and enhance what is known about the lived experience of the relationship transition in significant others caring for a partner with younger onset dementia. Institutional Review Board approval was granted by Molloy College.

A phenomenological inquiry approach utilizing Parse's method of dialogical engagement was the interview style (Parse, 1998). Face-to-face semi-structured interviews were conducted with nine women at a site of their choice during May 2016 through August 2016. Demographic

data about the caregivers and their partners were collected. Interviews were digitally recorded and later transcribed. NVivo 11 software was used to organize data and support coding data for the development of themes.

Participants

All of the research participants were women married to their spouses for 8 to 51 years, living together at home. Five of the participants are currently employed outside the home, three are retired, and one is on a leave of absence because of her caregiving responsibilities. The participants ranged in age from 49 to 73 years old with a mean age of 59 (n=8, as one participant did not respond to the question). Educational levels varied as follows: three with master's degrees, one with a bachelor's degree, and five with high school diplomas. Race/ethnicity indicated by participants was eight white and one black. Three of the participants stated they had serious financial concerns, one reported occasional financial worries, and four selected secure and worry free.

Results

The themes that emerged were: (1) The Way It Was Before Dementia, (2) A Maze of Uncertainty, (3) A Kaleidoscope of Feelings, (4) Shattered Dreams/Expectations, (5) A Solitary Journey, (6) The Struggle to Survive, and (7) Navigating Day-to-Day. Selected excerpts from the interview transcripts were used to illustrate the meaning of the themes as the subjects described their lived experience,

Summary and Recommendations

This study resulted in a greater understanding of the lived experience of relationship transition in significant others caring for a partner with younger onset dementia. Their stories were compelling as they conveyed their challenging daily experiences as caregivers, and

permitted the readers to better understand their daily struggles. The voices of the participants described their challenges, fears, hopes, and satisfaction that others would hear their stories. The richness of data gleaned from this study provides inspiration to further explore this topic with subjects of both genders, and diversity in ethnicity, religion, and socio-economic status. An additional recommendation is to conduct a study with both members of the dyad to broaden the understanding of relationship transition in couples dealing with younger onset dementia.

Dedication

This research study is dedicated to family caregivers who face the daily challenges of caring for a partner with younger onset dementia. The generosity of participants in the study provided me the opportunity to gain deeper insights into the experiences of a spouse living with a partner with younger onset dementia. Their courage and perseverance allowed me to capture and describe a perspective that can only be told by those experiencing the phenomenon. I am eternally grateful for the honor bestowed upon me to tell their stories. The following poem, by Langston Hughes (Hughes, 1990) may inspire the reader to think about what it is like to live with a partner with younger onset dementia before reading this dissertation.

Harlem By Langston Hughes

What happens to a dream deferred?
Does it dry up?
Like a raisin in the sun?
Or fester like a sore—
And then run?
Does it stink like rotten meat?
Or crust and sugar over—
Like a syrupy sweet?
Maybe it just sags like a heavy load.
Or does it explode?

Acknowledgements

The journey to obtaining a doctoral degree is one that is not traveled by many. It is a path fraught with opportunities, challenges, enlightenment, and hard work. While it is an individual who is granted this terminal degree, it is, in fact, an endeavor that is dependent on the support, guidance, mentorship, and inspiration of many. To that end, I would like to recognize my special team, those individuals who made it possible for me to accomplish this life-long dream.

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I owe a debt of gratitude to Charlotte Allen, a retired professor from the Social Work School of Gerontology at Molloy College, who graciously offered to serve as a content expert. She was instrumental in contributing valuable input to enhance the reliability and validity in the

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It would have been impossible to recruit subjects without the help of individuals who care for and have access to individuals with dementia and their families. Patricia Gaston from the Hudson Valley Chapter of the Alzheimer's Association, Connie Wasserman and Taylor Herbert from the Sid Jacobsen Jewish Community Center in East Hills, NY, and Joan Motley from the Alzheimer's Disease Resource Center in Suffolk County helped to distribute recruitment flyers. They enthusiastically supported this study and I look forward to dedicating future time to joining them in the fight against Alzheimer's. I admire and honor the great work they do.

On a personal level, I had the unwavering support of my family and close friends. I wish to honor my parents, Joan and Robert, who fostered my love of learning and always believed in my ability to succeed. My dear sisters, Nancy, Laura, Joyce, and Frances are interwoven in the fabric of my life and I am so thankful for their endless words of encouragement. Thank you to my loving daughters, Jennifer and Kristina, who have added more joy to my life than I could ever have imagined. Their unwavering belief that I could actually complete my Ph.D served as a guiding light.

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Chapter One: Statement of the Problem

Dementia is a degenerative brain disease characterized by a decline in memory, language, problem solving, and other cognitive skills that affects a person's ability to perform everyday activities (Alzheimer's Association, 2017). It is most frequently associated with Alzheimer's disease (AD). Problems with movement such as slowness, tremors, rigidity, and changes in gait are commonly found in Parkinson's disease dementia, but can also occur in individuals with AD (Bird, 2015). A distinct subset of dementia sufferers are afflicted with younger onset dementia (YOD), which accounts for approximately 5% of all neurodegenerative brain disorders (Alzheimer's Disease International, 2015; Bird, 2015). Although the list of differential diagnoses associated with younger onset dementia is extensive, frontotemporal dementia and early-onset familial Alzheimer's disease are the predominant causes of dementia in individuals younger than age 65 (Koedam, Lauffer, Van der Vlies, Van der Flier, Scheltens, & Pijnenburg, 2010). The term most commonly associated with dementia of all causes is Alzheimer's, adding to the stigma and confusion surrounding a diagnosis of a disease that has no known cure.

The cognitive, behavioral, and physical changes that occur as a result of dementia place a considerable strain on a couple's relationship (Galvin, Todres, & Richardson, 2005; Narayan, Lewis, Tornatore, Hepburn, & Corcoran-Perry, 2001; Simonelli, Tripodi, Rossi, Fabrizi, Lembo, Cosmi, & Perleoni, 2008). Research discloses that spouses predominantly serve as the primary caregiver for a spouse with dementia (Arai, Matsumoto, Ikeda, & Arai, 2007). According to the Alzheimer's Association (2017) over two-thirds of caregivers dealing with dementia are married, living with a partner, or are in a long-term relationship. Intimacy is recognized as essential to

relationship satisfaction and is an important variable in marital satisfaction (Yoo, Bartle-Haring, Day & Gangamma, 2014). While there are some research studies on caregivers and dementia, there has not been a focus on younger onset dementia. It is not known how significant others navigate changes in their relationships and intimacy with their partners afflicted with younger onset dementia. Therefore, a qualitative research study was conducted, guided by phenomenological methodology. Phenomenological studies seek to describe the common meaning for individuals of their lived experience of a concept or phenomenon (Creswell, 2013). The aim of this study is to highlight the issues of concerns for significant others caring for a partner with younger onset dementia and discover the meanings that they ascribe to the transition in their relationships. To truly enhance understanding of a phenomenon, the meanings must flow directly from those experiencing the phenomenon in their words and descriptions (Van Manen, 2014).

Background

Dementia is a term used to describe a broad spectrum of diseases which are characterized by cognitive and/or behavioral changes and functional decline, leading to a loss of independence. Although AD is the most common cause of dementia, symptoms of dementia can be attributed to a variety of etiologies such as vascular disease, frontotemporal degeneration, dementia with Lewy bodies, mixed dementia, stroke, brain tumor, traumatic brain injury and Parkinson's disease dementia (Alzheimer's Association, 2017). Prevalence and incidence data of dementia of all causes are grossly underreported due in part to inadequate valid and reliable measures with which to diagnose dementia in the early stages (Alzheimer's Association, 2017).

Most patients are prompted by family and/or friends to seek help from their primary care provider for cognitive and/or behavioral symptoms of dementia. Laske et al. (2014) report that research has shown non-specialist clinicians are inaccurate in diagnosing dementia causing further delay in obtaining an accurate diagnosis. Current diagnostic measures are not sensitive in early stages of dementia, although significant changes in the brain are already present. Furthermore, diagnostic measures are invasive, expensive and time-consuming, limiting their use as frontline screening. Currently, treatment is limited to a small number of medications that increase neurotransmitters in the brain; they help slow the progression of symptoms in some individuals with AD. None of the treatments available slow or stop the damage to neurons which ultimately make the disease fatal. Obtaining an early diagnosis may give patients and families time to learn about the disease and make critical life and financial decisions for the future, fostering an enriched quality of life for caregivers and persons with dementia. However, lack of effective treatment options may minimize the value of early diagnosis to the individual's disease trajectory and to population health (Morrissey, 2014).

Because of longer life expectancy, accompanied by an increased rate of dementia diagnosis, caring for persons with dementia is one of the largest global public health and social care challenges facing people today and in the future (Alzheimer's Disease International, 2015). The incidence of AD in Americans age 65 and older is projected to increase from 5.3 million to a projected 13.8 million by 2050 (Alzheimer's Association, 2017). The costs of health care and long term care for all individuals with AD and other dementias in 2017 are estimated at \$259 billion (Alzheimer's Association, 2017). The primary payers are government sponsored programs such as Medicare and Medicaid, covering approximately \$175 billion, or 67% of the

costs associated with caring for Americans older than 65 years of age with dementia. The remaining costs are covered by private insurance and self-pay by the individuals afflicted with dementia and/or their families. The astounding forecasted statistics prompted legislation to address this national health problem. The National Alzheimer's Project enacted in 2011, committed \$156 million in federal monies to develop a plan that addresses AD (Morrissey, 2014). The tenets of the plan included five main goals: prevent and effectively treat AD by 2025, enhance care quality and efficiency, expand support for families of persons with the disease, enhance public awareness and engagement, and improve data to track progress (Morrissey, 2014). The momentum stimulated by the National Alzheimer's Project is a significant step forward for dementia sufferers.

Research efforts have been focused on AD, the most common cause of dementia. Scientists are investigating the genetic and environmental causes of the spectrum of the diseases of dementia as well as searching for effective treatments; however, no known cure is on the horizon (Alzheimer's Disease International, 2015). Since the dismal predictions target adults over the age of 65 years, many studies examine the experience of family caregivers of older adults with dementia, primarily of the Alzheimer's type (Elvish, Lever, Johnstone, Cawley, & Keady, 2013; Forsund, Skovdahl, Kiik, & Ytrehus, 2014; Simonelli et al., 2008).

The forecast of the impending dementia crisis lacks data about the predicted numbers for those afflicted with younger onset dementia, neglecting a vulnerable population with unique needs (Alzheimer's Association 2015b). The most recent statistics reported by the Alzheimer's Association estimate that approximately 200,000 individuals under age 65 have younger onset AD (Alzheimer's Association, 2017). Furthermore, a delay in diagnosis is commonly seen in

cases of younger onset dementia due to the confusing and conflicting presentation of symptoms in the persons affected, and is frequently labeled as a psychiatric illness such as depression or anxiety (Koedam et al., 2010). Many of the impaired individuals afflicted with younger onset dementia are able to compensate for their deficiencies and, in essence, initially hide the disease process from loved ones and healthcare providers. The result is a prolonged period of time in which families struggle with behaviors that don't make sense and are often misdiagnosed as depression, anxiety, psychiatric disorders, substance abuse, and "mid-life crises" (Kuruppu & Matthews, 2013; Werner, Stein-Shvachman & Korczyn, 2009). The incidence of dementia during a younger stage of life is filled with social, financial, and occupational concerns, paramount for caregivers of significant others (Kuruppu & Matthews, 2013; Werner et al., 2009). Symptoms may result in loss of employment for one or both members of the dyad. Since significant others generally serve as the primary caregivers for an afflicted partner, this study will focus on the lived experience of significant others dealing with younger onset dementia in the context of an intimate relationship.

Intimacy

An integral concept in this study is intimacy; defined as an essential ingredient in adult personal relationships and assumed to be characteristic of the ideal type of marriage, as well as in other family relationships (Gaia, 2002; Schaefer & Olson, 1981). Intimacy is a multidimensional concept that encompasses a wide range of definitions and subjective interpretations, although the concept of intimacy is most frequently associated with sexual relations (Hook, Gerstein, Deterich, & Gridley, 2003). A growing body of knowledge about the role of intimacy in

relationships evolved in the 1950s, spurring a proliferation of interest in defining and measuring its importance.

Early theorists such as Erik Erikson, in his seminal work, *Childhood and Society* (1950), identified the ability to experience intimacy in a heterosexual relationship as a sign of a healthy personality. Intimacy is the “capacity to commit (one) self to concrete affiliations and partnerships and to develop the ethical strength to abide by such commitments, even though they may call for significant sacrifices and compromises” (Erikson, 1950, p. 263). The sixth stage of Erikson’s lifespan developmental theory identified the conflict of intimacy versus isolation. According to Erikson, complete, fulfilling, intimacy cannot be achieved outside the context of an adult heterosexual relationship. As such, the concept of intimacy is frequently associated with sexual relationships. In fact, Erikson associated intimacy with what he termed *genitality* based on the writings of Sigmund Freud, which supports the importance of sexual interaction as an integral component of intimacy in a heterosexual, love relationship. Other theorists such as Maslow classified intimacy as a motivational need essential to healthy emotional growth (Gaia, 2002).

The importance of intimacy in adult relationships has been well-studied in the disciplines of psychology, behavioral sciences, and marital counseling (Reis & Franks, 1994; Schaefer & Olson, 1981; Waring & Reddon, 1983). It is the elusive aspect of defining intimacy that complicates quantifying its role in healthy, mutually satisfying adult relationships. The prevailing value placed on intimacy in healthy relationships has prompted the search for tools to measure the levels of intimacy as experienced by individuals in adult heterosexual relationships. Schaefer and Olson (1981) developed the Personal Assessment of Intimacy in Relationships (PAIR) tool that was designed to measure five areas of intimacy: emotional intimacy, social

intimacy, sexual intimacy, intellectual intimacy, and recreational intimacy. The self-reporting tool is administered separately to each partner in a heterosexual relationship. The 36-items questionnaire requests that each individual rate each item on a Likert scale ranging from 1 (strongly disagree) through 4 (strongly agree); first on the perceived level of intimacy in the current relationship, and to repeat the questionnaire rating the items on the expected level of intimacy that they would like to have in their current relationship. The questionnaire is scored and the results are used to identify variations in perceptions to counsel couples seeking help with marital conflict/difficulty. Moore, McCabe, and Stockdale (1998) conducted a confirmatory factor analysis of the PAIR Inventory which failed to confirm validity and reliability reported by Schafer and Olson (1981).

Marital adjustment tools are designed to ascertain the perceived quality of the relationship of each member of the dyadic unit in order to facilitate counseling strategies to improve marital/relationship satisfaction. Therefore, the tools which measure relationship and/or marital satisfaction are not well suited to quantify the perception of relationship satisfaction from the perspective of a single member of a dyad, such as the significant other living with a person with younger onset dementia. In the absence of quantitative tools validated to measure relationship satisfaction in dementia caregivers, the majority of studies to date have examined relationship satisfaction in dementia caregivers using a qualitative approach (Davies, Newkirk, Pitts, Coughlin, Sridhar, Zeiss, & Zeiss, 2010; Kuppuswamy, Davies, Spira, Zeiss, & Tinklenberg, 2007; Morris, Morris, & Britton, 1988; Simonelli et al., 2008; Van Vliet, De Vugt, Bakker, Koopmans, & Verhey, 2010). Only one study conducted by Van Vliet et al. (2010) dealt with younger onset dementia.

Emotional intimacy

Sinclair and Dowdy defined emotional intimacy as “the perception of closeness to another that nurtures the sharing of personal feelings and includes expectations of understanding, affirmation, and demonstrations of caring” (2005, p. 193). An important aspect of social support includes the ability to share feelings and is associated with emotional intimacy. The closeness that couples feel can be expressed in non-physical, non-sexual ways such as smiling, gazing into each other’s eyes, saying I love you, caring gestures or just being present. The ability to express signs of affection is often lost in individuals afflicted with dementia.

Sexual intimacy

Sexual intimacy is defined by Schafer and Olson (1981) as sharing physical signs of affection and/or sexual activity. Discussions regarding sexuality and intimacy are rarely initiated by health care providers (Simonelli et al., 2008). Issues of sexual intimacy may be paramount to discussions with significant others who are dealing with younger onset dementia. Yoo and colleagues (2014) explored the variables of emotional and sexual intimacy, relationship satisfaction, and communication in 335 married couples recruited from the participants of a longitudinal study being conducted on family life, the Flourishing Families Project. The findings revealed that satisfaction with sexual intimacy correlated positively with satisfaction with the relationship and with emotional intimacy.

There are several factors that affect sexual intimacy in couples dealing with younger onset dementia. Behavioral changes in individuals with dementia, such as loss of inhibition, may be manifested by inappropriate sexual overtures and comments (Kuppuswamy et al., 2007). Sexual dysfunction may impact the couple’s ability to continue their previous patterns of sexual

intimacy (Kuppuswamy et al., 2007). Sexual desire may wane as significant others cope with issues of incontinence, feeding, and bathing (Portman, 2014). Changes in the balance of interdependence in a couple's relationship, as care giving responsibilities grow, impact the couple's sexual intimacy (Portman, 2014). Understanding how significant others caring for a person with younger onset dementia perceive sexual intimacy may help health care providers to engage in dialogue on a topic that is vitally important for the health and emotional well-being of the dyad.

Definition of Terms

Laying the groundwork for this study requires defining terms associated with dementia that can be easily misinterpreted; particularly, early stage dementia versus early-onset dementia (now more commonly known as younger onset dementia). Early stage dementia refers to newly diagnosed or mild beginning stages of the disease. The label of early stage dementia can be applied to all causes of dementia regardless of age at onset. Conversely, younger onset dementia is defined as a diagnosis of dementia before the age of 65 (Alzheimer's Association, 2006; Alzheimer's Association, 2017; Jarmolowicz, Chen, & Panegyres, 2015; Kuruppu & Matthews, 2013). For the purpose of this study, younger onset dementia will refer to the onset of dementia in individuals younger than age 65, regardless of etiology.

Alzheimer's disease (AD): Dementia of the Alzheimer's type is the most common cause of dementia and consequently the most widely studied. Progression of dementia of the Alzheimer's type is labeled in two stages; mild cognitive impairment (MCI) due to AD, and dementia due to AD (Alzheimer's Association, 2017). The criteria for pre-clinical AD is

proposed for research purposes, the stage in which there are measurable changes in the brain and possible cerebrospinal fluid and/or blood biomarkers, but the individual does not exhibit symptoms of dementia such as behavioral changes and/or memory loss. The value of blood as a potential source of biomarkers for AD is due to the absorption of cerebrospinal fluid into the blood with proteins associated with AD crossing the blood-brain barrier (Laske et al., 2104). However, blood based biomarkers for AD is not currently standardized for clinical implementation (Laske et al., 2104). MCI due to AD is the second stage. The afflicted individual experiences mild but measurable changes in thinking abilities that are noticeable to the person affected and to family members and friends (Alzheimer's Association, 2017). Persons with MCI are able to maintain independence with activities of daily living. Dementia from AD is characterized by noticeable memory, thinking, and behavioral symptoms that begin to impact the affected individual's ability to function in daily life (Alzheimer's Association, 2017). Additionally, other relevant terms for this study will be defined.

Early-onset Alzheimer's disease: Early-onset Alzheimer's disease (EOAD) is defined as dementia of the Alzheimer's type, diagnosed before the age of 65 accounting for approximately 5% of all cases of Alzheimer's disease in the United States (Gibson, Anderson, & Acocks, 2014). The terms younger onset and early onset dementia are used interchangeably in the literature to identify dementia in individuals diagnosed before age 65. The lower rates of incidence and prevalence have resulted in a paucity of studies in the experience of caregivers of EOAD populations. As such, little is known about the full scope of the problems associated with younger onset dementia (Alzheimer's Association, 2006; Alzheimer's Disease International, 2015).

Frontotemporal dementia (FTD): FTD has been reported as the most common neurodegenerative cause of dementia in those younger than 60 years old, and is equally as common as AD among those with dementia younger than 65 (Perry & Miller 2013). According to the National Institutes of Health (NIH), early-onset familial AD and FTD are listed as genetic and rare diseases at the Genetic and Rare Diseases Information Center (Retrieved from www.rarediseasesinfo.nih.gov, 3/21/2017). Familial AD is diagnosed based on family history when 2 or more family members have been diagnosed with AD (Bird, 2015). Familial AD is attributed to a mutated gene Apolipoprotein E (APOE- e4 gene), inherited from one parent, and tends to occur at a younger age (Bird, 2015).

Significant Other: A significant other is someone that you have a relationship with such as your husband, wife, boyfriend or girlfriend (Retrieved February 28, 2016, from [http://www.merriam-webster.com/dictionary/significant other](http://www.merriam-webster.com/dictionary/significant%20other)). A significant other is a person who is important to one's well-being, especially a spouse or one in a similar relationship (Retrieved February 28, 2016, from [http://www.merriam-webster.com/dictionary/significant other](http://www.merriam-webster.com/dictionary/significant%20other)). In this study, couples may be in heterosexual or same-sex relationships, married or not married but identify themselves as couples in committed relationships.

Caregiving: Caregiving is defined as attending to another individual's health needs (Alzheimer's Association, 2017). The responsibilities generally begin with assisting the individual with dementia with the instrumental activities of daily living (IADLs) such as household chores, shopping, preparing meals, arranging for doctor appointments, transportation, and managing finances (Alzheimer's Association, 2017). As the disease progresses, assistance progresses to helping with more personal activities of daily living such as dressing, bathing,

toileting, assisting with mobility, managing incontinence, and feeding. For the purpose of this study, family caregivers are referred to as informal caregivers as opposed to formal caregivers who are individuals hired to assist with caregiving activities such as home health aides.

Caregiver Burden: Caregiver burden is defined as the perceived stress associated with caring for an ill individual (Kang et al., 2014). Individuals experiencing caregiver burden may exhibit signs of poor psychological and physical health (Kang et al., 2014). For the purpose of this study, the terms, caregiver burden and caregiver stress, will be used interchangeably.

Relationship Transition: Relationship transition in this study will be defined as the changes that occur in an intimate relationship as a significant other assumes the role of caregiver for a person with younger onset dementia. The relationship transition will be explored from the perspective of the significant other serving as the caregiver.

Intimacy: The five categories of intimacy described by Schafer and Olson (1981) will be used as the multidimensional operational definition of intimacy in this study. The five categories of intimacy are emotional, social, sexual, intellectual, and recreational. Emotional intimacy involves the sharing of feelings and innermost thoughts. Social intimacy is having common friends, similar social networks and interest in sharing social activities. Sexual intimacy is the sharing of physical signs of affection and/or sexual activity. Intellectual intimacy is the sharing of ideas and engaging in intellectually stimulating conversations. Lastly, recreational intimacy is the sharing of hobbies and shared interest in sports and sporting activities.

Significance of Study

The predictions of the burgeoning number of people afflicted with dementia focuses primarily on those age 65 and over, failing to identify concern for increases in individuals with

younger onset dementia of all etiologies (Alzheimer's Association, 2017). The subset of younger onset dementia sufferers are further impacted by the chronic underinvestment in dementia research overall, diminishing hopes for effective treatments (Morrissey, 2014). Significant others caring for a partner with younger onset dementia may experience role transition as they assume the role of informal caregiver. Caregiving responsibilities include a diverse range of physical and emotional activities. Although, the tasks of caregiving for a person with dementia are similar to tasks provided to people with other conditions, dementia caregivers tend to provide more extensive assistance (Alzheimer's Association, 2017). It is not just the physical burden of care, but the loss of companionship that may affect dementia caregivers. An individual with dementia becomes a shell of the person who was once an intimate partner, and caregivers may grieve the loss of that person as a partner and confidante. Managing the behavioral changes associated with dementia such as aggressive behavior, wandering, depressive mood, agitation, anxiety, repetitive activity, and nighttime disturbances take a physical and emotional toll on dementia caregivers (Alzheimer's Association, 2017). Focusing solely on the physical aspects of caregiving fails to consider how couples negotiate their relationships as the symptoms of dementia progress. In addition, the dynamics of a marital relationship before dementia may certainly impact the trajectory of this role transition.

During an acute illness, the role of caregiver is expected to be temporary and of limited duration. However, caregivers of a person with younger onset dementia cope with a disease that is characterized by a progressive decline which is fluctuating in nature and follows an unpredictable course. The dynamic changes which occur in a person with dementia determine the level of care that is required. Although, symptoms may manifest similarly across the

spectrum of dementias, disease progression, behaviors, and response of caregivers may vary when compared to one another.

The subtle changes associated with younger onset dementia often precede diagnosis by 2-3 years and often precipitate feelings of uncertainty (Kuruppu & Matthews, 2013). The experience of caregivers of a person with younger onset dementia may be similar to that of caregivers of other diseases which are typified by cognitive, motor, and behavioral disturbances at a younger stage of life, such as Huntington's disease (Scerri, 2015) and victims of traumatic brain injury (Martin, 2012; O'Callaghan, McAllister, & Wilson, 2011). Scerri (2015) explored the psychological impact of care giving for a person with Huntington's disease. When a significant other serves as the primary caregiver, the dynamics of the relationship before dealing with illness may impact the trajectory of this role transition. Therefore, the experience of significant others dealing with younger onset dementia is an important focus for nursing research.

As significant others transition to the role of caregiver of a partner with dementia, it is important to understand the challenges from their perspective. Ducharme, Levesque, Lachance, Kergoat and Coulombe (2011) conducted a descriptive study to identify the challenges associated with the transition to caregiver role following disclosure of AD diagnosis. Common concerns included minimal support from family members and friends, lack of knowledge of support services, lack of preparedness in care giving skills, difficulty planning for the future, and the risk of caregiver burden.

The responsibilities and burdens placed upon caregivers have been identified as a critical concern in the literature (Gronning, Kristiansen, Dyre, Rahmani, Gyllenborg, & Hogh, 2013;

Jones et al., 2015; Judge, Yarry, Looman, & Bass, 2012). As informal caregivers play a vital role in the physical and psychological well-being, as well as safety of the care recipient, it is crucial to understand the challenges associated with caregiving. In addition, the health and well-being of the caregiver has been a focus of research seeking ways that health care providers can best support the physical and psychological well-being of both members of the dyad (Arai et al., 2007; Gronning et al., 2013; Mittelman & Bartels, 2013; Whitebird, Kreitzer, Crain, Lewis, Hanson, & Enstad, 2012; Zarit, Kim, Femia, Almeida, & Klein, 2013). Grief and loss have been identified as definable and measurable concepts in caregivers of persons with dementia (Marwit & Meuser 2002; Silverberg 2007). Dementia caregivers face an ambiguous loss; a loved one who is physically present but psychologically not the same or absent (Simpson & Acton, 2013). In addition, when dementia occurs during a younger stage of life, caregiving responsibilities can go on for decades, leading to a greater concern for developing caregiver burden. Instruments designed to measure caregiver burden play an instrumental role in furthering the understanding of caregiver perceptions and in identifying ways to support caregivers across the spectrum of diseases.

The coping strategies used by couples dealing with an acute or chronic illness affect the psychological well-being as well as the physical health of both members in a dyadic relationship. Younger onset dementia of all causes is a rare occurrence, yet it constitutes a subgroup of individuals and families who face distinct challenges. Although studies have explored such topics as caregiver burden, depression, anxiety, loss, etc., little is known about the meaning of relationship transition in significant others caring for a person with younger onset dementia.

Theoretical Framework

The lived experience of significant others caring for a person with younger onset dementia will be examined through the lens of transitions theory developed by Chick and Meleis (1986). Chick and Meleis (1986) proposed that transition as a concept is within the domain of nursing. The defining characteristics of transition include process, disconnectedness, perception, and patterns of response (Chick & Meleis, 1986). Transitions theory includes 4 major concepts: (1) the nature of transitions; (2) transition conditions (facilitators and inhibitors); (3) patterns of response; and (4) nursing therapeutics. Properties of the transition experience include: awareness, engagement, change and difference, time span, and critical points and events (Meleis, Sawyer, & Im, 2000). Im and Meleis (1999) described the development of a situation specific theory in identifying nursing phenomena limited to a specific population or field. Situation specific theories are designed to answer questions that are limited in scope and focus. Although much is known about transitions theory in general, little is known about the experience of the transition of the intimate relationship experienced by significant others caring for a person with younger onset dementia.

Research Purpose and Research Questions

The purpose of this study is to gain insight into the lived experience of relationship transition in significant others caring for a person with younger onset dementia. To better understand the lived experience of significant others caring for a person with younger onset dementia, the study focuses on three questions:

1. How does caring for a person with younger onset dementia affect the significant other's perception of the relationship?

2. What do significant others caring for a person with younger onset dementia identify as the important changes in their relationship?
3. What is the meaning of the transition in the relationship between a significant other and a person with younger onset dementia from the significant other's perspective?

Methodologies/Procedures

The study topic and the phenomenological research approach blend well to enhance the understanding of the lived experience of a significant other caring for a person with younger onset dementia. According to Creswell (2013), a phenomenological study describes the common meaning for several individuals of their lived experiences of a concept or a phenomenon. Phenomenology is based on a strong philosophical component. It is highly influenced by the writings of Edmund Husserl (1859-1938) and others who expanded on the views of Heidegger, Sartre and Merleau-Ponty (Creswell, 2013). Analyses of phenomenological studies conclude with a description of the essence of the experience for individuals incorporating *what* they have experienced and *how* they have experienced it (Creswell, 2013). The conclusion is referred to as the essence of the lived experience (Creswell, 2013). A qualitative research study was conducted using a phenomenological approach informed by the philosophical assumptions of Merleau-Ponty. According to Merleau-Ponty (1945/2014), "being-in-the world" refers to each individual's unique perception and experience with the world. Colaizzi's (1978) data analysis method was followed to identify themes within collected data. The researcher shared the analysis of the themes with the participants and sought feedback about the accuracy of the recorded findings. After obtaining approval from the Institutional Review Board at Molloy College, subjects were recruited using a purposive sampling approach through contacts with

support groups for significant others caring for a partner with younger onset dementia. Verbal and written consent was obtained prior to participant interviews. Semi-structured interviews were conducted in a setting selected by the participants.

Conclusion

Significant others caring for a person with younger onset dementia face unique challenges. There is little known about the relationship transition, as the role of caregiver evolves, from the perspective of the significant other caring for a person with younger onset dementia. Based on the literature review, the researcher believes that exploring the lived experience of a significant other caring for a partner with younger onset dementia may help bridge the existing gap in nursing knowledge. It is hoped that the findings from this research can be utilized to assist significant others in coping with the multiple changes occurring in their loved one and in their intimate relationship with the younger onset dementia partner.

Chapter Two: Review of the Literature

Chapter two will provide a synthesis and critical evaluation of the present state of the knowledge that addresses significant others caring for a person with younger onset dementia and relationship transition. The approach to the literature review in this study will be guided by the intent of qualitative research, to empower individuals to tell their stories in their own words (Creswell, 2013). This succinct review has enabled the researcher to avoid forming assumptions based on related studies and will allow the findings to emerge from the participant interviews. This chapter includes a review of the literature related to this study and is divided into four sections. The first section describes the complexity of the differential diagnoses of dementia and the diagnostic journey. The second section will explain the role of informal caregivers with a review of quantitative and qualitative studies of families, primarily focusing on significant others caring for a partner with dementia. The third section will explain relationship satisfaction and intimacy in the context of a significant other in an intimate relationship, caring for a partner with younger onset dementia. The fourth section will explain the concepts of grief and loss in the context of a significant other caring for a partner with dementia.

Dementia

The Diagnostic Journey

Dementia is an umbrella term used to identify a wide spectrum of neurocognitive disorders. In order to better understand the complexity of the diagnostic journey, a review of the primary causes of dementia follows. The process of providing a diagnosis for dementia symptoms is confounded by the multifactorial nature of causative agents as well as the array of

symptomatology. Clinical features are helpful in pointing towards a specific dementia disease, but are not conclusive for a definitive diagnosis. Although a delay in dementia diagnosis occurs in all age groups, it is more common in individuals manifesting symptoms of dementia in a younger life phase with behavioral changes often attributed to depression, stress, anxiety, and/or marital difficulties (Van Vliet, De Vugt, Bakker, Koopmans, & Verhey, 2010). Numerous studies have reported on the challenges patients and their families encounter when trying to find out the causes of cognitive, behavioral and/or movement disorders such as tremors and/or changes in gait, likening the process to negotiating a labyrinth (Samsi et al., 2014 ;Werner, Stein-Shvachman, & Korczyn, 2009). Results of a qualitative study of 27 people with cognitive impairment and 26 caregivers revealed that the assessment process was confusing, filled with long waiting times, prolonged anxiety, and culminating with an intense emotional experience upon receiving a diagnosis (Samsi et al., 2014).

Diagnostic Tools

Laske and colleagues (2014) stated the following: Scientific advances have increased the number of tools available to assist in diagnosing dementia, yet much is unknown about the temporal sequence of biomarkers during progression of disease. Currently, clinical diagnosis of AD is based on a thorough medical exam, neuropsychological testing, neuroimaging, cerebrospinal fluid analysis and blood tests. Invasive tests include obtaining a sample of cerebrospinal fluid by performing a spinal tap to look for the presence of proteins associated with dementia such as beta- amyloid. Neuroimaging such as magnetic resonance imaging (MRI) is less invasive but expensive. Based on these findings, the search for less invasive/expensive methods for screening and identifying disease in the early stage is a priority. Innovative tests

that may assist in early diagnosis include: analysis of subjective memory complaints, gait analysis, olfactory testing, and use of recorded speech to ascertain deterioration of spoken language. For example, since olfactory deficits have been found to correlate with AD and subjective memory complaints, a variety of methods are available to measure odor memory, threshold, identification, and discrimination. Olfactory assessment has a high sensitivity for AD but a low specificity since it is also seen in other neurological and psychiatric disorders.

The importance of early detection is supported by the findings that biomarkers of AD can be detected in the brains and cerebrospinal fluid in approximately 20-30% of cognitively healthy older adults (Laske et al., 2104). This finding confirms the hypothesis that changes in the brain precede clinical symptoms. In spite of advances in neuroimaging, cerebrospinal fluid biomarkers and DNA testing, examination of brain tissue during autopsy remains the “gold standard” for confirming a diagnosis of Alzheimer’s disease and frontotemporal dementia (Bird, 2015; Ghoshal & Cairns, 2013). Interestingly, it was during a post mortem examination that Alois Alzheimer discovered the presence of neurofibrillary pathology and unusual deposits in the cortex of an atrophic brain over 100 years ago (Alzheimer’s Association, 2017). More research is needed to validate the accuracy of biomarkers and identify which test or combinations of tests are appropriate to diagnose the cause of dementia.

The Role of Genetics

The role of genetics is unfolding as scientists advance the ability to study the human genome, with major advances in the understanding of the genetics of neurodegenerative disorders. Bird (2015) reported the following: specific gene mutations have been noted in early-onset familial AD manifested as multiple cases in one family. While 60% of early-onset AD is

familial, only 13% is found to be inherited in an autosomal dominant manner. The Apolipoprotein E (APOE) gene provides the blueprint for a protein that transports cholesterol in the bloodstream and everyone inherits one form of the APOE gene; e2, e3, or e4 from each parent (Alzheimer's Association, 2017). Researchers estimate that between 40 and 65 percent of people diagnosed with Alzheimer's have one or two copies of the APOE-e4 gene. However, while the association of the APOE- e4 gene with AD is significant, APOE genotyping lacks robust specificity and sensitivity. In approximately 75% of AD cases the cause is not known, leading to conjecture regarding the influence of genetic/environment interactions. Referral for genetic testing and genetic counseling is generally guided by the individual's family history.

Risk factors for AD include Mendelian genetic traits, genetic population risk factors as well as non-genetic risk factors such as cognitive reserve, education, and history of head trauma (Jarmolowicz et al., 2015). Gene mutations have been also been identified in cases of frontotemporal dementia (Ghoshal & Cairns, 2013). A recent study conducted by Jarmolowicz et al. (2015) revealed that over 70% of younger onset dementia is sporadic in nature with known gene mutations in only 1.6 % of the study population with younger onset AD and 7.3% of the study population with younger onset frontotemporal dementia. The researchers cited small sample size as a limitation in the generalizability of their findings.

Younger Onset Dementia

Younger onset dementia, previously known as early onset dementia, is defined as the development of the symptoms of dementia before the age of 65 (Van Vliet, De Vugt, Bakker, Koopmans, & Verhey, 2010). Younger onset dementia accounts for approximately 5 percent of all individuals diagnosed with dementia (Bird, 2015; Kuruppu & Matthews, 2013). A review of

the literature on the psychosocial impact of younger onset dementia was conducted by van Vliet et al. (2010). The search was performed in PubMed, PsycINFO, and Cinahl and included all publications up to October 2008. The search revealed only 17 articles reporting on studies conducted on younger onset dementia, noting significant limitations due to small sample sizes (Van Vliet et al., 2010). Symptoms associated with younger onset dementia are usually more severe, and individuals generally experience a rapid decline in cognitive and functional ability compared to those with late-onset dementia (Jarmolowicz, Chen, & Panegyres, 2015). Younger onset dementia is characterized by a variation in the presentation of symptoms with a higher propensity for changes at the neuropsychological level, such as severe praxis, executive, and language impairment, rather than memory loss (Ducharme, Kergoat, Antoine, Pasquier, & Coulombe, 2013). This distinction in disease manifestations contributes to a delay in diagnosis. While older adults may accept dementia as an expectation of normal aging, younger adults are unprepared for the shock of a dementia diagnosis (Robinson, Clare, & Evans, 2005). Although the differential diagnosis of younger onset dementia is extensive, Alzheimer's disease and frontotemporal degeneration are the most common.

Early Onset Alzheimer's Disease

AD is the most common cause of degenerative dementia for younger and older adults with the common presenting symptom of impairment of anterograde episodic memory (Koedam et al., 2010). However, early onset AD is not homogeneous in nature and may be accompanied by an atypical AD presentation. In a retrospective descriptive study of clinical characteristics of 270 patients with early-onset AD and 90 patients with late-onset AD, Koedam and colleagues (2010) found that the prevalence of non- memory presentations, such as difficulties in spatial

orientation and language impairment, is five times higher in early onset AD as compared to late onset AD.

Frontotemporal Dementia

Frontotemporal dementia (FTD), the second most common cause of younger onset dementia, encompasses a heterogeneous group of neurodegenerative diseases that selectively causes atrophy of the frontal and/or temporal lobes of the brain (Ghoshal & Cairns, 2013). FTD was first identified in the late 19th century by Arnold Pick; naming the entire spectrum of FTD diseases as Pick's disease (Warren, Rohrer, & Rossor, 2013). FTD encompasses a variety of clinical syndromes characterized by progressive changes in behavior and/or language: the behavioral variant of FTD (bvFTD) and two types of primary progressive aphasia (PPA): semantic variant (svPPA) and nonfluent variant (nfvPPA) (Perry & Miller, 2013). The predominance of language and behavioral symptoms in frontal temporal degeneration contrasts with the hallmark symptom of AD, which is memory loss. Individuals with bvFTD exhibit progressive changes in personality which may include apathy, disinhibition, eating behavior changes, impulsive behaviors, and lack of insight into their symptoms and /or behaviors (Perry & Miller, 2013). Language problems may include the impaired ability to speak such as slurring, or speech that may sound normal but the individual's ability to use or understand words is impaired (Perry & Miller, 2013).

Caregiving

Family members play a critical role in providing care for a loved one facing an acute and/or chronic illness, serving as an invaluable resource in meeting the physical and

psychological needs of their loved ones Current research about caregiving is limited in terms of generalizability, because of the prevalence of cross-sectional studies and the use of convenience samples, which often consist of more distressed, self–selected caregivers or highly motivated individuals with good health status (Grady & Rosenbaum, 2015). There is a lack of research on caregivers of individuals with younger onset dementia.

Role Norms

Caregiver characteristics have been explored to better understand those who serve as informal caregivers, and what influences a positive caregiving experience. From a review of the literature on caregiving (1999-2015), the majority of studies revealed that women primarily filled the role of informal caregiver of individuals with dementia. Gender role norms may contribute to the finding that the majority of primary caregivers are women (Allen, Goldscheider, & Ciambrone, 1999). Caregiving has been reported as an extension of women’s roles, and the skills required are unfamiliar to most men (Allen et al., 1999). Takano and Arai (2005) found that female caregivers of a spouse with early-onset Alzheimer’s disease were more likely to experience caregiver burden than male caregivers.

According to a study conducted by Allen and colleagues (1999), subjects who named their spouse as confidantes were three times more likely to name their spouses as their primary caregiver. Close positive relationships have been identified as a critical component of mutually satisfying caregiving relationships. Therefore, the ability to maintain emotional, as well as sexual intimacy, in a relationship faced with the changes associated with younger onset dementia, may be an important element fostering a positive caregiving experience. Exploring the distinctive needs of significant others dealing with younger onset dementia prompt the inquiry of how the trajectory

of caregiving is influenced by changes in intimacy in the couple's relationship as symptoms of dementia progress over time. Talking and sharing thoughts and feelings with a significant other is a natural occurrence which disintegrates as dementia progresses (Ducharme et al., 2013).

Gaia (2002) wrote about the uncertainty of the role of gender in the experience and expression of intimacy; yet gender differences are consistently noted in the literature. Possible explanations for gender differences include biological/evolutionary theories, role theory, social/psychological models and perceived differences in the meaning of intimacy. Underlying gender differences in communication styles may affect the intimate sharing of feelings, and further complicate understanding the challenges couples face in negotiating communication barriers associated with younger onset dementia.

A qualitative study examined how baby boomers (individuals born between 1947 and 1966) in Quebec, Canada perceived the role of caregiver, and if it differed from the previous generation (Guberman, Lavoie, Blein, & Olazabal, 2012). Although the years of the baby boom in Canada differ from the United States (1946-1964), the impact of social and historical changes appears similar. For the baby boomer generation in Canada, it became the norm for women to seek fulltime employment outside of the home and juggle the responsibilities of family caregiving with work obligations. In this new social context, family caregiving is not seen as the primary role, and baby boomers of both sexes have higher expectation of support services such as adult day care and home health services, to allow them to fulfill this dual role. This finding is relevant to caregivers of individuals with younger onset dementia who are primarily members of the baby boom generation, born in the United States between 1946 and 1964.

Caregiver Burden

The multidimensional response to the perceived stress of caring for an ill individual is called caregiver burden. It has been associated with depression, anxiety, insomnia and poor physical health for family caregivers (Kang et al., 2014). Caregiving may lead to loss of income, benefits, job security, and career opportunities (Grady & Rosenbaum, 2015). Changes associated with caregiving can lead to isolation, depression, and emotional and financial problems. Studies have examined a wide range of family caregiving situations.

Boland and Sims (1996) used a grounded theory design to understand the caregiving experience from the perspective of seventeen families providing care at home of varying intensity for individuals of all ages. The central theme that emerged was the description of caregiving as a solitary journey, with reports of isolation and aloneness in the majority of caregivers. This study excluded people with documented mental illness, AD and other dementias from the sample, possibly based on an assumption that these caregivers face unique challenges. The researchers recommended that the family, as a unit, should be explored in future research.

Burns, Quinn, Abernathy, and Currow (2015) conducted a study to identify characteristics of caregivers that may contribute to a worse than expected experience of caring for a family member at the end of life. Findings revealed two main factors: (1) intensity of care delivered, measured by the number of hours per day providing hands on care and (2) gender. Although the study did not focus specifically on dementia caregivers, the dependency associated with the trajectory of dementia can be associated with this finding.

Caregiver Burden in Dementia Caregivers

Research and meta-analysis on caregiver burden in individuals with dementia have been primarily quantitative in nature, and focus on topics such as transition to the role of caregiver (Ducharme, Levesque, Lachance, Kergoat, & Coulombe, 2011; Robinson, Gemski, Abley, Bond, Keady, Campbell,...Manthrope, 2011); coping strategies (Cooper, Katona, Orrell, & Livingston, 2008; Iavarone, Ziello, Pastore, Fasanaro, & Poderico, 2014); factors associated with caregiver burden (Arai, Matsumoto, Ikeda, & Arai, 2007; Gronning et al., 2013; Kang et al., 2014; Kim, Chang, Rose, & Kim, 2011); and caregiving styles (Corcoran, 2011). While the care provider-care recipient dyad has been studied across a wide range of diseases, the literature review on caregiving for this study will include studies conducted on family caregivers of individuals with dementia with a focus on what is available regarding younger onset dementia caregivers.

Transition

Transition is one of the concepts central to the discipline of nursing (Chick & Meleis, 1986, p. 238). Transition is described as the passage of one life phase, condition or status to another and encompasses the elements of process, time span, and a perception (Chick & Meleis, 1986, p. 239). During times of transition, individuals are at increased risk for illness and more likely to use unhealthy coping mechanisms (Meleis, Sawyer, & Im, 2000). Transitions associated with receiving a diagnosis of dementia or assuming the role of a family caregiver, may make caregiving individuals more vulnerable to illness (Meleis et al., 2000). Unhealthy transitions prevent individuals from mastering the skills and managing the emotions associated with the demands of a new role such as a family caregiver (Im, 2011). Nurses and other health

care providers can help facilitate healthy transitions by understanding the meaning of relationship transition in significant others caring for a partner with younger onset dementia.

Transition to Caregiver Role

In a descriptive study of 122 caregivers of elderly relatives with AD, it was found that the majority of caregivers felt unprepared for the role of caregiver, lacked informal support from family and friends, and suffered psychological distress dealing with their new responsibilities. Although only 44 participants were spousal caregivers, findings revealed that spouses reported using less problem-solving strategies and had more difficulty responding to disruptive behaviors (Ducharme, Levesque, Lachance, Kergoat, & Coulombe, 2011).

Robinson and colleagues (2011) conducted a systematic review of 35 qualitative and quantitative studies published from 2004-2009, regarding the topic of disclosure of the diagnosis of dementia. They found that younger people were unprepared for the diagnosis while many older adults viewed dementia as an expectation of the normal aging process. The shock of the diagnosis was further complicated by a lack of follow-up by health care professionals after diagnosis, and inadequate information about what to expect as the disease progresses (Robinson et al., 2011). This review reinforces the fact that there are differences in the needs of caregivers based on the age of dementia onset.

Kang and colleagues (2014) conducted a cross sectional study of 1,164 pairs of patients with AD and their caregivers, from the Clinical Research of Dementia of South Korea study cohorts. The results identified that severity of disease and functional impairment were significantly associated with higher care giver burden. The mean age of caregiver subjects was 74

years old, thereby limiting the generalizability to caregivers of individuals with younger onset dementia.

A higher level of perceived caregiver burden has been linked to an increased likelihood of institutionalization of the person with dementia (Kang et al., 2014). While this is distressing for the family and the person with dementia, it also contributes to substantial increases in overall healthcare costs. The estimated average cost of nursing home care for Medicare beneficiaries age 65 and older in the United States is \$81,125-\$92,378 per year (Alzheimer's Association, 2017). Juxtaposed to the financial impact of increased health care costs for individuals with dementia is the concern that existing medical care, home care, and community services may not be appropriate for individuals afflicted with dementia at a younger age.

Cooper, Katona, Orrell, and Livingston (2008) conducted a study to describe the relationship between caregiver burden anxiety, depression and coping style. This longitudinal study consisted of interviews with 93 caregivers of individuals with AD recruited from psychiatric services, the voluntary sector, and care homes in London and the South-East Region of England, conducted at baseline and one year later. The caregivers completed the Hospital Anxiety and Depression Scale, the Zarit Burden Scale, and the Brief Cope to measure coping strategies. The results showed the need for adapting the coping strategy to the specific situation and suggested that successful caregiving for people with degenerative disease probably involves using problem-focused coping strategies in situations that can be changed, and adapting emotionally to challenging behavioral symptoms (Cooper et al. 2008, p. 935). Iavarone, Ziello, Pastore, Fasanaro, & Poderico (2014) conducted a quantitative study of 86 caregivers of individuals with AD recruited from the Memory Clinic of the Neurological Unit of AORN

Cardarelli Hospital in Naples, assessing caregiver burden, anxiety levels, and coping strategies. They identified that the primary caregiver is more often a woman who is physically, emotionally and financially overwhelmed by her role.

Caregiving in Younger Onset Dementia

The majority of caregivers of young and middle-aged adults are spouses of similar age who frequently experience severe disruption in their professional, family and social lives which may impact their mental and physical health (Grady & Rosenbaum, 2015). During this younger stage of life, caregiving responsibilities may affect the parenting role and family dynamics, since children may still be living at home. Limited studies have been done on the impact of caring for people with younger onset dementia. Individuals with younger onset dementia are usually working and caring for children and/or older parents. Managing family life with a spouse with younger onset dementia is usually accompanied by serious psychological and emotional difficulties for the persons afflicted, as well as their families (Werner et al., 2009).

Loss of independence, as the dementia symptoms change over time, has a profound influence on the personal relationships between partners and family members (Werner et al., 2009). As symptoms of the disease progress, loss of employment triggers a loss of financial income. However, beyond the financial implications, the impact on the individual's self-esteem, self-efficacy, and sense of self-worth can be devastating. Unique characteristics of younger onset dementia include financial insecurity, high stigmatization, and negative effects on marital quality; yet there are limited services geared to meet the specific needs of families coping with younger onset dementia (Werner et al., 2009). Several studies have been conducted to help

identify the most effective ways to support families caring for individuals with younger onset dementia.

The NeedYD- study (Needs in Younger Onset Dementia) is a longitudinal observational study that was designed to delineate the course of early onset dementia, the functional characteristics and needs of younger onset dementia patients and their caregivers, the risk factors of institutionalization, and the interaction with the caring environment (Van Vliet, Bakker, Koopmans, Vernooij-Dassen, Verhey, & DeVugt, 2010). Data were collected at six month intervals over a two year period in a sample of 215 younger onset dementia patients and their family caregivers. While final results have not been published, a subset of the sample was analyzed regarding the use of formal and informal care (Bakker, de Vugt, van Vliet, Verhey, Pijnenburg, Vernooij-Dassen, & Koopmans, 2013). A significant finding of this analysis was that caregivers of individuals with younger onset dementia delayed the use of formal care services until the disease was in the advanced stages, and experienced the double burden of work and care responsibilities. The delay in accepting formal care services may be related to the stigma of dementia at a younger age, as well as the lack of specialized services designed to meet the needs of younger onset dementia dyads.

A dyad recruited from the NeedYD study participants was the focus of a single case study, conducted to explore the unmet needs of a 59 year old male with younger onset Alzheimer's and his 46 year old wife, and the caregiver's experiences of transitions in care and health services (Bakker, de Vugt, Vernooij-Dassen, van Vliet, Verhey, & Koopmans, 2010). Specific issues identified included the following: lengthy time in obtaining a diagnosis, lack of

fit between needs and services available, impact on the caregiver's outlook for the future, and the need for health care services to meet the changing needs across the disease/caregiving trajectory.

Ducharme, Kergoat, Antoine, Pasquier, and Coulombe (2013) conducted a qualitative study to explore the unique experiences of spouses in early onset dementia. Twelve spouses of a partner diagnosed with dementia before the age of 65 participated in semi-structured interviews conducted by mental health professionals. The researchers reported that subjects expressed the gradual loss of autonomy and inability to accomplish conjugal and family daily tasks had numerous repercussions on the socio-professional, financial, and psychological dimensions of family life. Similar to Bakker and colleagues (2010), common themes that emerged included: long time to diagnosis, difficulty managing day-to-day activities, and difficulty planning for the future. Ducharme and colleagues (2013) found that the subjects in their study voiced concerns about managing behavioral and psychological symptoms, grief for loss of spouse, denial of diagnosis, and hesitancy to tell others about the diagnosis of dementia.

Using a quantitative approach, Kaiser and Panegyres (2007) conducted a cross-sectional cohort analysis of survey responses completed by 100 spouses of patients diagnosed with younger onset dementia who were registered with the Neuroscience Assessment and Care Clinic in Western Australia. The Zarit Burden Interview and the Beck Depression Index were administered to assess the response to the three main manifestations of dementia: cognitive, behavioral, and functional decline. The mean age of respondents was 62.3 yrs., primarily women (54%). Key findings revealed more depression in spouses of individuals with frontotemporal dementia, primarily linked to behavioral changes; husbands reported less distress than wives, wives reported slightly higher levels of depression than husbands, and functional decline limited

spousal activity in both genders. It is not disclosed in the study if husbands and wives differ in the use of supportive psychosocial services. A unique finding reported in the results is the high response on the Beck Depression Index noting caregivers' reduced interest in sexual activities.

Rosness, Mjorud, and Engedal (2011) also reported higher levels of depression noted in caregivers of individuals with frontotemporal dementia, suggesting the contributory factor of anosognosia, i.e. the affected individual's lack of insight into their behavior/mental health condition. In a descriptive study, 49 caregivers either married or cohabiting (unmarried but living together) completed the Quality of Life-Alzheimer's Disease Scale and the Geriatric Depression Scale and provided demographic information. Although limited in generalizability due to the small sample size, they found that being married was significantly associated with depression. The authors hypothesized that being married may indicate a more emotional, intimate relationship, possibly of longer duration, with a history of shared responsibility for family and future planning.

The literature consistently identifies the significant role of intergenerational dynamics in families coping with younger onset dementia due to the demands of caring for children, aging parents, as well as having a spouse with dementia. Role identity and the transition from partner to caregiver appear to be markedly different in younger adults taking on the caregiver role; therefore, interventions for supporting caregivers must take into consideration the unique needs of the caregiver of a significant other with younger onset dementia.

Caregiver Burden in Younger Onset vs. Late-Onset Dementia Caregivers

Several studies have explored the experience of caregiver burden for family caregivers of individuals with younger onset versus late-onset dementia (Arai, Matsumoto, Ikeda, & Arai,

2007; Ducharme, Lachance, Kergoat, Coulombe, Antoine, & Pasquier, 2015; Gronning, Kristiansen, Dyre, Rahmani, Gyllenborg & Høgh, 2013). Arai and colleagues (2007) surveyed 68 dyads (14 were patients with younger onset dementia and 54 with late-onset dementia) using a self-administered questionnaire that included socio-demographic data and information about the caregiving situation. Since the study took place in Japan, the Japanese version of the Zarit Burden Interview was used to measure caregiver burden. The findings reported caregivers of individuals with younger onset dementia experienced higher caregiver burden, a longer duration of caregiving, less social support, and greater perceived difficulties related to patients' behavioral symptoms.

Using Meleis' nursing theory of transition as a theoretical framework, Ducharme et al. (2015) interviewed 48 caregivers of two groups: 1) younger than age 60, and 2) older than age 70. The caregivers completed psychometrically sound instruments measuring variables believed to relate to caregiver transition. Women tended to be the primary caregivers in both groups. The younger caregivers reported that they were managing more severe impairments, but felt more prepared and better informed about available services. Based on the study findings, the researchers recommended that interventions should be personalized, based on the age of onset of the person affected with dementia. This study highlighted the divergent needs in younger onset versus late-onset dementia caregivers.

Gronning and colleagues (2013) conducted a quantitative case-control study with 42 patients, matched according to disease severity, in order to analyze caregiver burden in matched groups of younger onset and late-onset AD. Caregiver burden was assessed by analyzing the responses to the Neuropsychiatric Inventory (NPI), the Activities of Daily Living scale, and the

Utilization of Resources in Dementia Care scale. The findings concluded that caregivers of individuals with younger onset dementia had a longer duration of caregiving and higher caregiver burden. According to Gronning et al. (2013), even though the group with late-onset dementia needed more assistance with ADLs, the caregiver burden was greater in the group of caregivers of individuals with younger onset dementia, with the additional dimension of socioeconomic impact. The findings of higher caregiver burden and longer duration of caregiving concurred with the results of a study conducted by Arai and colleagues (2007) comparing the experience of younger onset versus late-onset dementia caregivers.

Individualized support services were identified as a key strategy to reduce caregiver burden in this population. A limitation of both studies was small sample sizes and both were conducted in countries other than the United States. Socio-cultural factors and diverse health care delivery systems may limit the generalizability of the findings.

Caregiver Assessment Tools/Support Strategies

The valuable role of caregivers in dementia care has led researchers to seek ways to quantify caregiver stress in order to guide, prioritize, and target needed areas of support for caregivers of individuals with dementia (Czaja, Gitlin, Schulz, Zhang, Burgio, Stevens, Gallagher-Thompson, 2009; Mittelman & Bartels, 2013; Zarit, Kim, Femia, Almeida, & Klein, 2013; Whitebird, Kreitzer, Crain, Lewis, Hanson, & Enstad, 2012). The development of interventional support strategies is intended to improve the health and well-being of caregivers and facilitate their ability to continue to serve in the role of primary family caregiver.

In an effort to identify needed areas of support for caregivers of persons with dementia, the Risk Assessment Measure (RAM), a brief 16 item tool, was designed to assess six domains

linked to caregiver risk: depression, burden, self-care and health behaviors, social support, safety, and patient problem behaviors (Czaja et al., 2009). The tool was tested on a diverse sample of 642 dementia caregiver dyads and confirmed that each of the six domains significantly related to at least one of the selected concurrent validity measures. Caregiver demographics included Hispanic, African-American, and Caucasian subjects with 80% of the caregivers being female and 55%-79% married. Although the results support the benefit of using the RAM in research, community, and clinical settings, the authors identify factors, such as financial and social strains that are not assessed in the tool, which warrant further investigation.

Farran, Miller, Kaufman, Donner, and Fogg (1999) conducted a study to develop a tool to measure/assess the positive aspects of caring for persons with Alzheimer's disease. Based on a multiphase research study, the Finding Meaning through Caregiving Scale (FMTCS) was designed, based on interviews with 94 dementia caregivers, resulting in six major themes forming three subscales: loss/powerlessness, provisional meaning, and ultimate meaning. In phase two, a shortened version of the tool, developed by conducting internal consistency analyses, was administered to a convenience sample of 46 dementia caregivers (91% married, 71% female & mean age 65.53 yrs.). In the third and final phase, a larger sample of dementia caregivers was surveyed with a range of relevant measures to establish the psychometrics properties of the FMTC, and to identify the kinds of coping strategies employed by families dealing with dementia. Confirmatory analysis was strong for construct validity of all three subscales, and confirmed the reliability and validity of the tool. The researchers identified that conceptual overlap may exist when responses reveal simultaneous feelings of loss/powerlessness while subjects report the

ability to find positive meaning in caregiving. Longitudinal studies are suggested to identify at what point feelings of loss/powerlessness may lead to despair.

Collins, Crump, Buckwalter, Hall, Gerdner, and Kudart (1995), reported on the experiences of gero-psychiatric nurses examining the effectiveness of the Progressively Lowered Stress Threshold Model with caregivers of family members with dementia, using a control/intervention group study design. The researchers voiced concern about the researchers' ethical responsibilities to balance the needs of the subjects with the quest to assure reliability and validity of the data. The use of denial as a coping mechanism may influence subject response with false assurances that everything is fine. The expectation that subjects will be able to acknowledge and report their personal and intimate responses to the challenges of daily experiences of caregiving reinforces the need for researchers to be cognizant of subjects' level of anxiety and be prepared to offer them support services. This introduction into the topic of denial as a coping mechanism leads to the next section on coping strategies.

Coping Strategies

Many researchers have studied coping strategies and the impact of emotion on family caregivers of a person with dementia to develop effective interventions (Iavarone, Ziello, Pastore, Fasanaro & Poderico, 2014; Judge, Yarry, Looman, & Bass, 2012; Moore, Ozanne, Ames, & Dow, 2013; Simpson & Acton, 2013 and Van Mierlo, Meiland, Van der Roest, & Drees, 2012). According to Iavarone and colleagues (2014), coping strategies may be categorized into three main types: task-focused, emotion-focused, and avoidance-focused. Task-focused coping uses action to remove a problem or make it better, emotion-focused strategies seek to regulate distressing emotions, and avoidance coping involves circumventing adverse

situations. Findings in the study conducted by Iavarone et al. (2014) indicated that the reliance on emotion-focused strategies led to higher levels of distress for caregivers, while successful caregiving seemed to be associated with task-focused and avoidance-focused strategies. However, the study did not take into consideration the impact of the behavioral and psychological symptoms of dementia on caregiver burden and distress, limiting the causal relationship between coping strategies and caregiver distress.

In contrast, Moore and colleagues (2013) focused on how family caregivers respond to the behavioral and psychological symptoms of dementia in a study of interviews of twenty-five (11 spouses, 14 adult children, 84% female) caregivers of a family member with dementia including completion of the Neuropsychiatric Inventory (NPI) and the NPI-Distress scale. The conclusion identified the need to educate and support caregivers to identify triggers, understand symptoms, and learn to cope with the challenges of behavioral and psychological symptoms. The researchers stated that there is a gap in translating evidence based strategies into practice for family caregivers of a person with dementia and nurses can play a pivotal role in the education and support of family caregivers.

Judge, Yarry, Looman, and Bass (2012) developed an innovative intervention for family caregivers of individuals with dementia. A single protocol was developed called *Acquiring New Skills While Enhancing Remaining Strengths (ANSWERS)* which combined educational skills (traditionally used with caregivers), and cognitive rehabilitation skills training (traditionally used with individuals with dementia), to address the dyad's care issues and needs. Cognitive status of the 118 individuals with dementia in the study was assessed using the Mini Mental Status Exam (MMSE). The mean score on the MMSE (0-30) was 22.96, suggesting mild-to-moderate

symptoms of dementia in the 118 individuals with dementia in the study. Specifically compared to control group participants, caregivers enrolled in the intervention arm of the study experienced less emotional health strain, less dyadic relationship strain, less role captivity, and improved caregiver mastery. The findings from this study concur with the literature reviewed; dementia caregivers face unique challenges, and are often ill-prepared to cope with the physical and emotional tasks associated with caregiving.

Simpson and Acton (2013) explored the stress of caring for individuals with dementia in the framework of the concept of emotion work, the interactions between two people intended to enhance emotional well-being and provide emotional support. Emotion work can also refer to changes in one's feelings, as well as outward expressions to meet social expectation. "A diagnosis of dementia disrupts the dynamics of family relationships as family members cope with an ambiguous loss, a loved one who is physically present but psychologically absent (Simpson & Acton, 2013, p. 53)." The dissonance between how caregivers feel and how they believe they should feel often leads to anxiety, guilt, and stress. Based on a secondary analysis of 11 interviews conducted for a pilot study of a sleep intervention for caregivers and a qualitative study exploring caregiver mastery, transcripts of informal caregivers of a person with dementia were analyzed to identify the role of emotion work in day-to-day living. As the caregiving journey evolves, it is important to understand how caregivers handle feelings as they strive to be good caregivers, for the health and well-being of both members of the dyad.

Duggleby, Swindle, Peacock, and Ghosh (2011) conducted a mixed methods study to explore hope, transitions, and quality of life in 80 family caregivers of persons with AD. The aim of the study was to examine the relationship among demographic variables, hope, quality of

life, and transitions of family caregivers of persons with AD. For the purpose of this study, the operational definition of transitions was described as the processes individuals use to integrate significant changes into their life. The qualitative arm of the study used five open-ended questions to capture the experience of caregiver transitions. A major theme reported was the feeling of being isolated. Access to information about the disease process was found to be associated with a higher quality of life for the caregiver.

A descriptive study conducted by Ducharme, Levesque, Lachance, Kergoat, and Coulombe (2011) focused on the experience of 122 caregivers at the time of receiving a diagnosis of AD for their family member and the impact on effective coping in the caregiver role. Using Meleis' theoretical framework for role transition, the objectives of the study were to document the characteristics of the caregiving context during the transition to the caregiver role following diagnostic disclosure of Alzheimer's disease, and to compare these characteristics by caregiver gender and kinship tie to relative. The researchers identified gender and kinship variation in the caregiver perception of feeling prepared to provide care, and a lack of knowledge of available resources. The study findings identified the valuable role of psycho-educational interventions in facilitating effective role transition.

Nurses play a vital role in promoting a healthy transition to the caregiver role by assessing support needs and caregiving abilities, and by providing early psycho-educational interventions (Ducharme et al., 2011). The unpredictable nature of the trajectory of progressive cognitive loss presents discrete challenges to those who serve as caregivers. Enhancing understanding of the emotional response experienced by caregivers to the reality of the diagnosis

of dementia offers an opportunity to improve the experience for the caregiver and the care recipient.

Relationship/Couplehood

Relationship satisfaction is perhaps the most commonly studied and influential variable in the study of romantic relationships (Graham, Diebels, & Barnow, 2011). Consensus regarding the definition of various terms to define relationship satisfaction such as quality, adjustment, and happiness is confounded by the fact that measures of these constructs are highly correlated with one another. Interdependence is a prominent feature of relationships between two people and has been explored primarily in the context of marriage or romantic involvement. According to Rusbult and Buunk (1993), the presence of interdependence implies that partners in a close relationship influence one another's experiences and need each other to obtain valued outcomes such as support in the functions of day-to-day living, affection, sexual fulfillment, and emotional closeness. Interdependence is the sharing of roles and responsibilities within a relationship and is closely associated with mutuality, reciprocity, and commitment. Satisfaction level and degree of dependence are two important properties of close relationships which play an important role particularly in understanding how couples balance interdependence to meet the needs of each individual (Rusbult & Buunk, 1993). Couples establish unique patterns of interdependence within their relationship that is disrupted when faced with younger onset dementia.

The benefits of interdependence can be psychological health, a sense of well-being, and achievement of mutually desired outcomes between individuals when needs are met. Zhang, Yeung, Fung, and Lang (2011) examined the relationship between loneliness, peripheral social partners (partners outside the marital relationship), and interdependence in 365 Hong Kong

Chinese individuals, aged 18-91 years old. Individual beliefs regarding independence and interdependence were identified as influential in the experience of loneliness and highly affected by cultural beliefs. Zhang and colleagues (2011) proposed that more interdependent people may be able to reduce loneliness not only with emotionally close partners, but also with peripheral partners; whereas, less interdependent people would tend to rely less on peripheral partners in dealing with loneliness, especially as people grow older and prioritize emotional goals. Since one of the positive consequences of interdependence is a sense of psychological well-being, it is important to identify how individuals perceive the value of emotionally close social partners. Findings from this study extended the literature by showing that peripheral partners could also be beneficial in the form of reducing loneliness for at least some middle-aged and older adults, especially those with a stronger sense of independence (Zhang et al., 2011). Loneliness associated with changes in the marital relationship as the symptoms of dementia progress may be mitigated, if caregivers are able to get emotional needs met in other social relationships.

Tools developed to quantify the concept of relationship satisfaction have been used primarily in couples seeking marital counseling (Graham, Diebels & Barnow, 2011; Hook, Gerstein, Detterich, & Gridley, 2003; Schaefer & Olson, 1981). In addition to robust description of the sample demographics, the dynamic nature of studies of relationship satisfaction compels researchers to calculate, report, and consider the reliability scores used in their research (Wilkinson & the Task Force on Statistical Inference, 1999).

Graham and colleagues (2011) conducted a reliability generalization study to determine how reliable the measures of relationship satisfaction compared across different samples and study characteristics. A reliability generalization meta-analysis concerning the reliability of

seven relationship satisfaction tools: the Locke- Wallace Marital Adjustment Test (LWMAT), the Kansas Marital Satisfaction Scale (KMS), the Quality of Marriage Index, the Relationship Assessment Scale, the Marital Opinion Questionnaire, Karney and Bradbury's (1997) semantic differential scale, and the Couples Satisfaction Index was conducted by Graham et al. (2011) to assist researchers in deciding which measure of relationship to use in their studies. Graham et al. (2011) reviewed 1,031 articles published about the seven relationship tools, starting with the earliest reference, Locke and Wallace (1959), to 2007.

While Cronbach's alpha provides evidence of the reliability of a tool, when deciding on the appropriate measure to use in conducting research on relationship satisfaction, there are other factors such as characteristics of the test taker and influences of the setting in which the tool is administered, which affect the reliability of the measure (Graham et al., 2011). There are limitations to applying the concept of reliability induction, i.e. assuming data collected in a new study possesses acceptable reliability based solely on the reliability found in previous studies. One overarching element identified was the need for researchers to be extremely diligent in describing their samples in published research, stressing its importance in supporting the strength of their findings. Of the measures examined, the KMS appears to be the strongest overall measure on the basis of reliability and brevity. However, the authors stressed the importance of not using the measure of reliability as the sole determining factor in selecting a tool to measure relationship satisfaction. The specific item content, factor structure, validity, and sensitivity to change of different measures may be better to use based on the focus of the study.

The majority of measures of relationship satisfaction have been tested with a focus on marital counseling and family therapy (Ascher, Strum, Seider, Holley, Miller, & Levenson,

2010; Graham et al., 2011; Hook, Gerstein, Detterich, & Gridley, 2003; Locke & Wallace, 1959; Moore, McCabe, & Stockdale, 1998; Schaefer & Olson, 1981). Only one study (Ascher et al., 2010) was found using a marital satisfaction tool in couples dealing with younger onset dementia. Ascher and colleagues (2010) studied the impact of two types of dementia on marital satisfaction and on the emotional language which spouses use during marital interactions that involve conflict. Subjects recruited from the Memory and Aging Center at the University of California in San Francisco included spouses from 15 FTD couples, 16 AD couples and a control group of 21 couples who were neurologically healthy. Marital satisfaction was measured with the Locke-Wallace Marital Adjustment Scale, while the use of emotional language was evaluated by audiotaping each couple having a conversation about an area of conflict in their relationship. The results supported the researchers' hypothesis, i.e., couples dealing with the behavioral symptoms associated with frontotemporal dementia reported lower levels of marital satisfaction and used more negative emotional language regardless of dementia severity. Since the mean age of frontotemporal dementia and AD couples was under the age of 65, this study is relevant to the research being conducted for this dissertation.

Shim, Landerman, and Davis (2011) conducted a secondary analysis of longitudinal data on variables of care relationship mutuality collected from 91 caregivers of a family member with AD or Parkinson's disease (PD) enrolled in the control group of a randomized trial of caregiving skill training. The participants included 187 dyads (102 AD and 85 PD dyads) of which 80% were women and 71% were spousal caregivers. The conceptual definition of mutuality was the degree of caring, affection, intimacy, mutual concern, and overall relationship satisfaction, which was assessed using the Mutuality Scale of the Family Care Inventory. The findings revealed that

lower mutuality was associated with more depressive symptoms in caregivers and higher mutuality increased the likelihood that family members continued to serve in the caregiver role. A limitation of the study was the small number of participants relative to the large number of variables. The overarching conclusion was that relationship satisfaction promoted positive caregiving experiences and improved care-recipient outcomes.

Satisfaction in relationships has been linked to effective communication patterns while ineffective communication leads to relationship dissatisfaction (Yoo, Bartle-Haring, Day, & Gangamma, 2014). Three hundred and thirty five married couples were recruited from a longitudinal study of family life in a large northwestern city in the United States, to explore the variables of communication, emotional intimacy, sexual satisfaction, and relationship satisfaction. While the findings revealed that satisfaction with sexual intimacy correlated positively with satisfaction with the relationship and emotional intimacy, effective communication was identified as the common thread associated with overall relationship satisfaction. Changes in an individual's ability to communicate due to the symptoms associated with dementia, may influence satisfaction with the relationship for both partners, with distinct implications for significant others caring for a partner with younger onset dementia.

Using a qualitative approach, Massimo, Evans, and Benner (2013) interviewed the wives of two individuals with probable frontotemporal dementia who were patients at a cognitive neurology clinic in a large university health care setting in the Northeastern United States. Some of the themes that emerged were social isolation, loss of shared understandings, anger related to the lack of emotional responsiveness/apathy of the ill partner, and the challenge of staying emotionally connected. The researchers propose that providing an opportunity for caregivers of

FTD partners to express their anger may help them cope with the social and emotional losses that occur with their partner's behavioral changes. Relationship satisfaction is important to the spousal caregiver and the partner with younger onset dementia, leading several researchers to investigate interventions that include both members of the dyad.

Dementia researchers are beginning to focus on the couple as a unit (Hain, Touhy, Compton Sparks, & Engstrom, 2014; Ingersoll-Dayton, Spencer, Kwak, Scherrer, Allen, & Campbell, 2013). Although, the loss of couplehood has been identified as a significant issue in spousal dyads dealing with dementia, few interventions have focused on the couple as a unit. An intervention of creating a life story book was adapted from a palliative care model, in a study of 24 couples living with a spouse diagnosed with dementia (Ingersoll-Dayton et al., 2013). The intervention consisted of five sessions designed to evoke positive memories shared by the couple, and provided an opportunity for the couple to engage in a pleasurable activity. The couples were mostly in long term relationships with a mean caregiver age of 72.2, mean care recipient age of 74 and mostly (65%) female caregivers. Findings highlighted the concept of ambiguous loss, grieving while someone is still with you. Collecting mementos and photos, while pleasurable, evoked feelings of sadness in some caregivers and care recipients about losses both present and future. Feedback from the caregivers revealed the impact of the loss of communication and shared meaning within a previously intimate relationship. An important aspect of the intervention was framing the interviews on the positive aspects of the couples' relationships in order to highlight the couple's relatedness, adaptability, and resilience over the years. The researchers reported that the activity promoted intimacy and they observed increased physical touching in some participants.

In another study considering the concept of couplehood, Hain et al. (2014) conducted a phenomenological study to understand the experience of living with early stage dementia of the Alzheimer's type from multiple perspectives, including the individual, the spouse, and the couple as a dyad. Six couples with a mean age of 79 years participated. Interviews with the persons with dementia revealed their recognition of changing abilities and trying to do the best they could in managing day-to-day. Interviews with spouses exposed five themes: living with frustration, taking one day at a time, hoping against hope, living with losses, and the burden of increased responsibilities. Interviewing the spouse and the person with dementia separately allowed for caregiver concerns to be addressed, and enhanced the couple's dialogue when interviewed together. The researchers concluded that understanding the specific needs of each couple facilitates the development of interventions tailored to their unique needs with a greater likelihood of positive outcomes. Therefore, considering the impact of previous patterns of communication and interdependence in couples' relationships are important in order to understand how couples dealing with younger onset dementia negotiate the temporal experience of disease progression and relationship satisfaction.

Intimacy

Intimacy has been described as an integral element needed for mutual satisfaction in a wide range of adult relationships extending from casual friendships to unmarried and married couples. The concept of intimacy is identified as an essential ingredient in adult personal relationships and assumed to be characteristic of the ideal type of marriage, as well as in other family relationships (Gaia, 2002; Schaefer & Olson, 1981). The sixth stage of Erikson's lifespan developmental theory identifies the conflict of intimacy versus isolation (Erikson, 1950).

According to Erikson (1950) intimacy is an individual's capacity to commit to partnerships with the ethical strength to stand by such commitment, even if it requires significant sacrifices and/or compromises. Complete, fulfilling intimacy is explored in the context of adult heterosexual relationships and subsequently associated with sexuality (Erikson, 1950). Other theorists such as Maslow classified intimacy as a motivational need essential to healthy emotional growth (Gaia, 2002). In a more modern approach, the definition of relationships has been broadened to include same-sex and unmarried couples (Graham et al., 2011).

The multidimensional components of intimacy originally described by Olson (1975) included seven categories : (1) *emotional intimacy*- experiencing a closeness of feelings; (2) *social intimacy*- the experience of having common friends and similarities in social networks; (3) *intellectual intimacy*-the experience of sharing ideas; (4) *sexual intimacy*- the experience of sharing general affection and/or sexual activity; (5) *recreational intimacy*- shared experiences of interests in hobbies, mutual participation in sporting events; (6) *spiritual intimacy*- the experience of showing ultimate concerns, a similar sense of meaning in life, and/or religious faiths; and (7) *aesthetic intimacy*-the closeness that results from the experience of sharing beauty (Schafer & Olson,1981).

Schaefer and Olson (1981) identified that many of the tools available to measure intimacy were too global and focused on marital satisfaction measures or measured closely related, but dissimilar, concepts such as group cohesion or self-disclosure. The PAIR (Personal Assessment of Intimacy in Relationships) was developed to assess the degree of intimacy that an individual perceives he or she has with another person.

This self-report inventory measures the expected versus realized degree in five areas of intimacy: *emotional intimacy*, *social intimacy*, *sexual intimacy*, *intellectual intimacy*, and *recreational intimacy*. The domains of *spiritual* and *aesthetic* intimacy were dropped because they were conceptually and empirically unclear. The PAIR attempts to: (1) identify the degree to which each partner presently feels intimate in the various areas of the relations (realized); (2) identify the degree to which each partner would like to be intimate (expected); and (3) is scored and plotted in such a fashion that direct feedback can be given to a therapist and the couple about their perceptions and expectations in the relationship. The scores have meaning within each of the partner's perceived and expected degrees of intimacy and also in terms of the differences between the two partners.

The association of intimacy as a component of love prompted the quest for scales to define and quantify the dimensions of intimacy to assist counselors to working with couples in the context of therapy (Hook, Gerstein, Detterich, & Gridley, 2003). They proposed that intimacy is a multidimensional concept consisting of four specific components: love and affection, personal validation, trust, and self-disclosure. Hook and colleagues (2003) examined whether three popular intimacy measures assessed these four components, and if men and women differed in their experiences of intimacy through the lens of a Western world, heterosexual, love dyadic point of view. Three scales, the Miller Social Intimacy Scale (Miller & Lefcourt, 1982), the Personal Assessment of Intimacy in Relationships Scale (Schaefer & Olson, 1981), and the Fear of Intimacy Scale (Descutner & Thelen, 1991) were administered to 360 undergraduate students in counseling courses. Factor analytic procedures were conducted to examine the multidimensional components of the three popular intimacy measures resulting in a

four factor solution explaining 48.7% of the total variance. The results identified limitations in the use of a single scale. The findings supported the researchers' hypothesis that men and women differ in how they experience intimacy. Since the subjects were recruited from an undergraduate student cohort enrolled in counseling courses, it is difficult to speculate if the conclusions would be similar in middle-aged adults coping with dementia.

The overall quality of the marital relationship has been another measure that has been used to assess the caregiver experience, particularly in examining caregiver burden and depression. A cross sectional, correlational pilot study conducted by Williams (2011) examined the relationship between marital quality, marriage duration, caregiver burden, and depression in caregivers married to a spouse with AD. The sample consisted of 16 caregivers (5 men and 11 women) from South Florida, ages 55 and older. A key finding of the study was a greater risk of depression, poor marital quality, and caregiver burden in new caregivers, identifying this stage of caregiving as a time of increased vulnerability, and a population that warrants development of interventions to support caregivers during this period.

Galvin, Todres, and Richardson (2005) conducted a single case study of a husband's experience as the primary caregiver for his wife diagnosed with AD. Analysis of the interviews disclosed the complexity of being a spousal caregiver and produced three themes: something is wrong, the challenging shared journey, and coping through meaning-making and advocacy. The story revealed the ebbs and flows in the journey and illustrated the changes in the husband's relationship with his wife, as she became more dependent and he assumed an active role as caregiver and advocate. Poignant examples of how the couple established their relationship in new ways, such as showering together as a way of maintaining intimacy, were included. The

authors emphatically stressed the importance of hearing the unique experiences of individual caregivers in their own words to develop true person centered plans of care.

Since close positive relationships have been identified as a critical component of mutually satisfying care giving relationships, it is important to understand the role intimacy plays in couples dealing with younger onset dementia. Sexual intimacy is not often in the forefront of the studies reviewed. This may be due to the discrete nature of conversation about the topic.

Sexual Intimacy

Sexual intimacy includes signs of affection through physical touching and /or sexual activity. It is well accepted that sexual intimacy that is mutually satisfying is a key ingredient in relationship satisfaction (Hook, Gerstein, Detterich, & Gridley, 2003). Yet, there has been limited exploration of how sexual intimacy is affected in couples dealing with dementia.

Simonelli, Tripodi, Rossi, Fabrizi, Lembo, Cosmi, and Perleoni (2008) noted that health care professionals avoided discussions of sexual concerns unless the issue was raised by the patient and/or caregiver. This silent avoidance of sexual concerns fails to provide an opportunity to help couples cope with changes in sexual intimacy that may be associated with dementia. Changes in sexual function affected by illness impacts the quality of life for couples dealing with dementia and needs to be included in discussions with health care professionals (Simonelli et al., 2008).

Using a semi-structured interview, Simonelli et al. (2008) investigated the affective and sexual dimensions in partners caring for an individual with AD. A group of one hundred AD caregivers recruited from three Geriatric Centres of Rome, Italy was compared with a control group matched for age, sex, education and marital status on measures collected in the semi-structured interview and completion of the Caregiver Burden Inventory Scale. The average age

of dementia patients was 74.69 (SD=5.537) with age of diagnosis, 71.15 (SD=5.641), and with the majority (90%) of patients in the mild to moderate stages of disease. Based on the study's literature review, the researchers expected that many caregivers may try to maintain a sexual relationship as a means of coping with their partner's illness and may find sexual intimacy to be a source of support and reassurance. The majority of caregivers were women between the ages of 55 and 85. Incidence of sexual dysfunction was similar in caregiver and control groups but caregivers who were more stressed had sex less frequently. Gender differences were notable as male caregivers reported having more frequent sexual intercourse, while female caregivers placed a higher priority on the affective and care aspects of the marital relationship.

Further exploration of the impact of dementia on sexual function and relationships is provided by findings in a study by Kuppuswamy, Davies, Spira, Zeiss, and Tinklenberg (2007). Interviews were conducted with 50 couples in which one partner was diagnosed with probable or possible AD. They were recruited from the Stanford/VA Alzheimer's Center in California. The mean age of caregivers was 69.3 (SD=8.4), with 32 female and 18 male caregivers. The results showed a wide range of responses from continuing to enjoy a satisfying sexual life, struggling with the changes, and accepting the loss of sexual intimacy as a consequence of dementia. Similar to the findings reported by Simonelli et al. (2008), sexual and physical intimacy were identified as being very important to couples dealing with dementia.

Using a focus group approach, Davies, Newkirk, Pitts, Coughlin, Sridhar, Zeiss, and Zeiss (2010) interviewed fourteen dementia and nine mild memory impairment caregivers recruited from the Stanford/VA Alzheimer's Research Center in California. The majority of the spousal caregivers for both groups were female Caucasians. The themes derived from the focus

group interviews were: communication, marital cohesion, affection expression, caregiver burden, and ambiguity about the future of the relationship. Both groups reported that physical expressions of intimacy were important even if sexual intimacy was not present. The researchers emphasized that the pre-morbid pattern of sexual intimacy in a couple's relationship played a significant role in how couples negotiated sexual intimacy with the onset of mild memory impairment or dementia.

Portman (2014) explored the topic of sexual intimacy in spouses of individuals with Alzheimer's disease in his book, *The Ethics of Sex and Alzheimer's*. He exposes the moral dilemmas associated with sexual activity, fidelity, and unmet emotional needs in spouses married to a partner with AD. The narrative is based on theological writings, societal norms, and high profile cases, such as Nancy Reagan and Justice Sandra Day O'Connor. Portman went on to say that it is an assumption that married couples engage in consensual sex that is mutually satisfying. The sanctity of marriage is explored through the lens of the spouse who according to Portman (2014) is married to Alzheimer's. He used the term "married to Alzheimer's" to denote a new lifestyle that is beyond one's control, possibly introducing thoughts of divorce or desertion. The suffering of a spouse caring for a partner with AD is characterized by loneliness and emotional exhaustion. He explored societal and theological norms and expectations of fidelity in marital relationships with the overarching goal of understanding how spouses caring for a partner with dementia meet their own emotional and sexual needs. The appropriateness of sexual intimacy between a spouse and a partner afflicted with dementia is discussed specifically related to the capacity of the individual with dementia to consent, raising moral and ethical concerns. The complexity of sexual intimacy in couples dealing with dementia is fraught with judgments about

the actions of spouses seeking the solace of sexual and/or emotional relationships outside of the marital relationship and/or continuing sexual relations with a spouse with questionable ability to consent. The ubiquitous theme is the importance of sexual intimacy in emotional health and well-being for individuals across the lifespan. Furthermore, dealing with dementia poses unique challenges for caregivers and care recipients to meet their individual needs for sexual intimacy.

Although the findings of the studies reviewed acknowledge the importance of sexual intimacy for couples coping with mild memory impairment and/or dementia, none of the studies focused on couples dealing with younger onset dementia. Research is needed to understand the needs of significant others serving as caregivers for a partner with younger onset dementia, so that interventions can be developed to help maintain relationship satisfaction, decrease caregiver burden, preserve quality of life, and delay or avoid placement in an institutional setting (Davies et al., 2010).

Loss and Grief in Dementia Caregivers

The onset of dementia symptoms is a catalyst for a series of losses for family caregivers and the individuals afflicted (Silverberg, 2007). The concept of loss has been discussed in previous sections and is found as a common theme in many studies surrounding the care giving experience for family members of an individual with dementia. However, this segment will focus on caregivers' response to the losses associated with dementia caregiving and what is known about the grieving process in this distinct population.

Ford, Linde, Gigliotti, and Kim (2012) conducted a phenomenological case study to understand the lived experience of three wives caring for husbands with dementia with a particular focus on how female spousal caregivers defined, processed, and grieved their losses.

The subjects ranged in age from 51 to 84 years old. The youngest subject was caring for her husband diagnosed with frontotemporal dementia while the two older wives were caring for husbands with AD. In addition to face-to-face interviews, the researchers administered the Marwit-Meuser Caregiver Grief Inventory (MM-CGI). The authors reported that the most significant findings related to grief and loss, with variation in response attributed to possible generational differences (Ford et al. 2012, p. 143). All three wives described marriage as a partnership and expressed feeling that everything rested on their shoulders. Losses identified included the loss of growing old together and loss of a normal family life. Generational differences were found in the ability to express grief with the youngest participant grieving most normatively, while the oldest participant scored the highest on the MM-CGI indicating the need for support services. This finding may be attributed to younger adults being more open to asking for help while older adults may be less comfortable in expressing grief and seeking assistance. In addition to the small sample size, this study is limited in generalizability because of the homogeneity of the subjects. The researchers identified the need for education, counseling, and mental health services to assist spouses caring for a person with dementia in dealing with feelings of stress, burden, and changes in their relationship with the person with dementia. Albeit the small sample size, this study provided a wide range of suggestions for future research such as longitudinal, large-scale studies to examine age as a predictive variable for the significance of caregiver grief as well as the impact of providing targeted services to younger individuals with dementia.

Forsund, Skovdahl, Kiik, and Ytrehus (2014) conducted a qualitative study to explore and describe spouses' experiences of losing couplehood with their partner with dementia living

in institutional care. Using a grounded theory design, the central theme of the loss of a shared lifetime emerged with three main categories; loss of a shared past, loss of a shared everyday life, and loss of a joint future. Feelings varied from day-to-day and were influenced by how spouses identified themselves, as part of a couple (we) or as a separate individual (I). The study characteristics: small sample size (n=10), older participants, and marriages lasting longer than 40 years, limits the generalizability to caregivers of individuals with younger onset dementia living at home. In addition, the experience of physical separation may have a significant impact on the experience of loss.

According to Marwit and Meuser (2002), the recognition of grief as a definable and measurable concept pertaining to persons with AD and their caregivers had only recently appeared in the professional literature. Based on caregiver comments, the authors prepared a 50-item instrument called the Marwit- Meuser Caregiver Grief Inventory (MM-CGI) which is comprised of three factors: personal sacrifice burden, heartfelt sadness and longing, and worry and felt isolation. The MM-CGI was administered to a robust sample that included 83 adult child caregivers and 83 spousal caregivers who were recruited from the Memory and Aging Project (the clinical research arm of the Alzheimer's Disease Research Center at the Washington University School of Medicine). The MM-CGI items were found to be psychometrically sound using factor analysis, demonstrated high internal consistency and reliability (Cronbach's alpha=.96), and appeared valid when compared to validated instruments for depression, caregiver strain and well-being, and perceived family support. Since low scores may be associated with caregiver denial, this tool may be helpful in exploring its' presence. The MM-CGI was proposed for use as a diagnostic tool for identifying areas open to constructive intervention.

Silverberg (2007) illuminated how grief is imbedded in the family member's experience of providing care for individuals with AD and related dementias (ADRD). Based on a review of the literature (1924-2006) on the topic of grief and its relationship to families dealing with dementia and her own personal experience, Silverberg (2007) developed a new intervention model called the 3-A Grief Intervention Model for Dementia Caregivers: **A**cknowledge, **A**ssess and **A**ssist. Silverberg identified two unique characteristics of grieving associated with dementia caregiving, denial as a coping strategy and the use of respite as key factors in the family caregiver's grief experience. Silverberg (2007) noted that caregiver stress could lead to the caregiving duties not being carried out appropriately, putting the care recipient at risk for neglect.

Similar findings concerning the grieving process have been identified in caregivers of persons with disorders of consciousness such as traumatic or anoxic brain injury. Disorders of consciousness are also referred to as vegetative state (VS) or minimally conscious state (MCS) (Cruzado & Elvira de la Morena, 2013). The objective of the study was to explore the relationship between coping strategies and prolonged grief disorder (PGD) in 48 caregivers of patients with disorders of consciousness. Similar to caregivers of individuals with dementia, caregivers of individuals with VS or MCS presented high levels of distress and used denial as a coping mechanism. Denial of the situation and the outlook for the future, along with the experience of guilt and self-blame associated with the disease, predicted the presence of PGD in the caregivers.

Summary

This literature review provides evidence of the devastating effect of dementia on family caregivers. Nine studies reviewed focused on caring for a partner with younger onset dementia

compared to thirteen studies on late-onset dementia and thirteen studies that included both younger onset and late-onset dementia sufferers and caregivers. The underpinning of caregiver burden and negative psychosocial impact on significant others caring for a partner with younger onset dementia is a common thread in the nine studies reviewed. All nine studies which explored the needs of individuals afflicted with younger onset dementia revealed that their needs differ, but each of them reported limited statistical significance due to a small sample size and homogeneous subject characteristics. The literature review revealed a gap in what is known of the phenomenon of relationship transition as experienced by significant others caring for a partner with younger onset dementia. This is important for several reasons. First, caregiver health and well-being is related to care recipient health and well-being. Secondly, younger onset dementia occurs in a life phase that is generally characterized by active careers, social and physical activities, demands of parenting, fewer co-morbid illnesses, and expectations of planning for the future. Finally, few resources are designed for couples dealing with younger onset dementia. Since there are no valid and reliable tools to assess the impact of dementia on relationship satisfaction in younger adults, it is vital to explore the lived experience of relationship transition in significant others living with a partner with younger onset dementia. Research on the lived experience of significant others caring for a partner with younger onset dementia is important for nurses and other health care providers to develop effective interventions that may help support them through their unique relationship transition.

Chapter Three: Research Design and Methods

Overview of Data Collection and Analytic Framework: Phenomenology

Analytic Framework

The primary epistemological basis for qualitative research is the human experience (van Manen, 2014). Phenomenological research describes the subjective experiences of individuals sharing a common phenomenon but does not attempt to analyze or explain (Creswell, 2013). The “lived experience” is a central methodological component of the phenomenological method that aims to provide concrete insights into the qualitative meanings of phenomena in people’s lives (van Manen, 1997). According to Creswell (2013), a phenomenological study describes the common meaning for several individuals of their lived experiences of a concept or a phenomenon. The phenomenological approach is to suspend all judgments about what is real until it is revealed as described by the individuals experiencing the phenomena (Creswell, 2013). A distinctive feature of phenomenology is the description of the basic elements of the human experience from a first person point of view in contrast to the use of the third person perspective that dominates scientific knowledge (Merleau-Ponty, 1945/2014).

Phenomenology has a strong philosophical component and is highly influenced by the writings of Edmund Husserl (1859-1938) and others who expanded on his views, such as Heidegger, Sartre and Merleau-Ponty. The philosophical underpinnings provide a framework for researchers to seek understanding of the content of experiences in the abstract way individuals experience living in the world (Merleau-Ponty, 1945/2014). Phenomenology is practiced through a sense of wonder and an empathetic participation in the world (van Manen, 2014).

Perception of the human experience is not just a mental state but how individuals ascribe meaning to tangible things (Merleau-Ponty, 1945/2014). For example, predictions concerning the clinical course of an illness offer limited insight into how people actually experience the course of the illness (van Manen, 2014). Following a phenomenological method opens the mind and heart of the researcher to see a human experience through the lens of the individual living the phenomenon. Findings from a phenomenological study conclude with a summative, descriptive passage that discusses the essence of the experience for individuals describing what they have experienced as well as how they have experienced it (Creswell, 2013). A description of the essence is the culminating aspect of a phenomenological study (Creswell, 2013). The phenomenological method was selected for this study because the topic of study is a human experience that cannot be measured in quantitative terms but must be described as seen through the eyes, and felt in the hearts, of the individuals living through the experience. Phenomenology provides the opportunity to discover knowledge about a human experience where little is known about how individuals reflect on its meaning (van Manen, 2014).

Research Aim

The purpose of this study was to gather knowledge about the experience of relationship transition in significant others caring for a partner with younger onset dementia. The interviews were conducted to elicit information about how caring for a partner with younger onset dementia changes the relationship with that person, and also, to find out what that means to the caregiver.

Study Design

This qualitative research study used a phenomenological inquiry approach utilizing Parse's method of dialogical engagement. The process of dialogical engagement is not an interview but a discussion between the researcher and participant that focuses on the phenomenon under study, as it is expressed by the participant (Parse, 1998). Parse espoused the critical element of true presence in the interview process. True presence is a special way of being attentive to evolving changes in meaning as the researcher thoughtfully listens to the life experience as described by the individual living and experiencing the phenomenon.

This research study was based on a naturalist paradigm using the qualitative tools of observation, questioning, and description (Rubin & Rubin, 2012). Naturalists assume subjects will have different frames of reference and seek to discover how the participants see the phenomenon being studied (Rubin & Rubin, 2012). This researcher served as the primary instrument and therefore was an active participant. As the instrument, the researcher must gain the trust of the subjects and be perceived as authentic in the quest for information about the subjects' lived experiences (Creswell, 2013; Polit & Beck, 2012).

Sampling Method

Sampling in phenomenological studies is generally conducted using a criterion sampling method (Polit & Beck, 2012). Criterion sampling uses a purposive approach, selecting cases that meet a predetermined criterion of importance (Polit & Beck, 2012). The primary requirement is that subjects must have experienced the phenomenon and be willing and able to communicate what it is like to live or have lived through the experience (Polit & Beck, 2012). The number of subjects in a phenomenological study is generally small, between 10-12 participants (Polit &

Beck, 2012). To investigate the diversity in individual experiences, phenomenological researchers strive to recruit participants with demographic or other differences (Polit & Beck, 2012). The researcher attempted to recruit male and female participants from a range of ethnic, socioeconomic, and educational backgrounds.

A convenience sampling technique based on a criterion sampling methodology was used to recruit participants who utilized support groups and/or support services for caregivers of individuals with younger onset dementia in the New York area. Snowball sampling, selection of participants through referrals from earlier participants was also used to recruit subjects (Polit & Beck, 2012). Word of mouth referrals were accepted by professional colleagues and personnel at the support group agencies to recruit subjects who met the inclusion criteria, but may not be associated with a support group for caregivers of individuals with younger onset dementia.

Participant Inclusion Criteria

The primary criterion to participate in this study was for the subject to be a significant other living with a partner diagnosed with dementia before the age of 65, for at least five years. Subjects invited were married or cohabiting with a significant other in either a heterosexual or same sex relationship. Participants were in a committed relationship for at least five years. It was assumed that couples who are in a relationship for at least five years have a shared history and would be able to speak to the experience of relationship transition. Participants were all English speaking and able and willing to participate in 1-2 interviews lasting approximately 1-2 hours. The participants were the self-identified family caregiver/care partner for a significant other diagnosed with younger onset dementia. No specific time frame since diagnosis was required. There is often a delay in receiving a formal diagnosis of dementia in younger adults

and significant changes may occur prior to obtaining a formal diagnosis (Samsi et al., 2014). It was assumed that significant others may be able to speak about relationship transition regardless of the time frame since receiving a formal diagnosis.

Exclusion Criteria

Participants who have placed their partner with younger onset dementia in a long term care facility/institutional setting were excluded from the study. Several studies have identified the unique stresses and emotions associated with deciding to place a family member in a long term care facility; the findings reveal how family members describe the transition from caring for a family member at home to their role as a caregiver when their family member is placed in an institutional setting (Davies, 2005; Eriksson & Sandberg, 2008; Kraijo, De Leeuw, & Schrijvers, 2014; Silverberg, 2011). It was assumed that significant others dealing with a partner in institutional placement may experience different relationship transition issues.

Significant others caring for a partner with younger onset dementia related to a diagnosis of traumatic brain injury were excluded. Although, younger onset dementia may be attributed to traumatic brain injury there are two factors that may affect the experience of caregivers. Traumatic brain injury is related to an acute event while younger onset dementia of other causes is insidious, occurring over a longer span of time. Expectations for recovery and the overall prognosis may vary in individuals with traumatic brain injury (O'Callaghan, McAllister, & Wilson, 2011). It was assumed that significant others caring for a partner with younger onset dementia due to a traumatic brain injury may experience different relationship transition issues.

Study/Steps and Plan

Recruitment Strategies

The researcher contacted the coordinators of support groups for caregivers of individuals with younger onset dementia to distribute invitational flyers at a chapter of the Alzheimer's Association in the NY area and a community center in Nassau County, NY (Appendix A). Permission to post the flyer on the agencies' web sites was sought and obtained. Potential participants were invited to join the study and advised to email or call the researcher if they were interested to set up a meeting time and place of their convenience. They were informed that location may be a public location or in their home.

Ethical Considerations

Confidentiality

Human subjects' research requires specific consideration of the rights of subjects. In accordance with ethical and legal requirements, Institutional Review Board (IRB) approval was obtained from Molloy College. The researcher obtained permission from the agencies that coordinate the support groups for individuals with younger onset dementia granting approval to distribute invitational flyers to the support group participants. Any personal identifying information such as address, family names, and places of employment and names of care providers/care services was not collected during the interview. Pseudonyms were instead used for all data collection. Participants were assured of strict confidentiality and guaranteed that all data will be de-identified. Participants were assigned a code (starting with #1) to assure that all data was de-identified. All data was treated as confidential and stored in a secure file in the

researcher's home office. Participants were advised numerous times that participation was voluntary. Participation or declining participation did not have any effect on their support group status. Being a member of a support group was not required for participation in this study.

Consent

All subjects were asked for verbal consent prior to obtaining written consent. IRB approved consent delineated the purpose of the study and any potential risks/benefits of participation for the subject (Appendix B). The approved consent form was signed by participants, in-person, and prior to the start of each interview. A hard copy of the consent form was given to each participant. Participants were informed of their right to withdraw from the study at any time without any type of penalty. Participants were reassured of strict confidentiality and that all data would be de-identified.

Potential Risks

There were no physical, psychological, social or legal risks anticipated by being a participant in this study. Subjects volunteered to participate and agreed to share their experiences to whatever degree they choose. Their participation was brief or more extended, as they determined. They were asked to share the experiences that they selected. Individuals who volunteered had the legal ability to give their own consent. It was possible that the topics participants chose to discuss were emotional in nature. The sensitive nature of the research topic compelled the researcher to have a list of referrals for psychosocial support services. Participants were referred to the 24/7 Helpline (1-800-272-3900) provided by the Alzheimer's

and Dementia Caregiver Center. The researcher provided a list of support groups within their communities as requested.

Potential Benefits

There were no direct benefits derived from participation in this study. It is possible that the participants found a personal benefit in having the opportunity to talk about their situation. They may also have found that by participating in this study they might have a clearer understanding of the study topic and offer help to others in a similar situation.

Data Collection

A convenient date, time, and location were chosen by the participants. Locations for the interviews varied and participants were able to schedule at a community private location such as a library, a college office, a separate room at the support center, or within the participant's home as desired. Only the participants were present with the researcher during the interview. Participants were asked to sign the consent prior to the start of each interview (Appendix B). Participants were asked to complete a demographic form prior to the interview beginning (Appendix C).

Interview

Semi-structured interviews were conducted after the participants had signed the IRB consent form and completed the demographic form. The demographic data form took approximately 10 minutes to complete. Participant interviews lasted between thirty-nine minutes and two hours. In-depth qualitative interviewing, one of the key naturalistic research methods was used to collect data (Rubin & Rubin, 2012). Through interviews, researchers learn about the

experiences, motives, and opinions of others, and discover perspectives through the lens of another individual about phenomenon the researcher have never experienced (Rubin & Rubin, 2012). Participants were interviewed using six questions as prompts (Appendix D). Flexibility is an important component in collecting qualitative data. Therefore, the researcher was guided by the response of the participants and discussion of topics of importance to each individual participant. The interviews were recorded using a digital voice recorder. The researcher took field notes with permission of the participants. The researcher listened to each recorded interview within 24 hours. Participants were offered a follow-up visit/interview to discuss the summary of the transcript. Follow-up with participants offered them the opportunity to add any additional information or delete any reported statements they made if desired. It also gave the researcher the chance to clarify information, seek additional information, and validate the researcher's understanding of the collected data. Follow-up was conducted at the convenience of the participants and included communication by phone and/or email.

Costs to the Participants/Compensation

There was no cost to the participants for taking part in this study. Participants were provided with a \$15 gift card after each interview was completed.

Data Transcription

A confidentiality agreement was signed by the transcription service (Appendix E) prior to the transfer of any study data. The digitally recorded interviews were sent electronically to a trained transcriptionist. When the transcribed interviews were returned, the transcripts were stored and organized using NVivo11 software.

Journal

The researcher began using a journal starting with the first interview to record field notes and analytical memos. Each entry was dated and timed. The journal was used throughout the research process until data had been fully coded and summarized. Entries in the journal included the researcher's ideas related to the progress of the research, observations of participant's non-verbal cues, and feelings experienced by the researcher during the interviews. Keeping notes in a journal helped the researcher to remember details that may seem unimportant at the time but become relevant as the research progresses (Polit & Beck, 2012). As anticipated, writing in a journal throughout the study added to the richness of the data and enhanced the development of themes.

Field Notes

The researcher took field notes during the interviews and throughout the research process. Notes included comments about the ease of access to subjects and the discussions that occur when appointments for interviews are being made (Bazeley, 2013). Descriptive notes recorded by the researcher during the interviews included observations of participants' body language and expressed emotions such as crying or laughing, as well as key words and phrases stated during the interview. Field notes are important to record the physical and social context of events relating to the study (Bazeley, 2013).

Analytic Memos

Memos are recorded in the process of conducting qualitative research to help the researcher achieve an analytical detachment from the raw data and to help guide the researcher to

conceptualize (Groenewald, 2008). In essence, these analytic memos describe the researcher's reflections on what he/she is learning from the data (Groenewald, 2008). Memos contribute to the credibility of the qualitative research process (Groenewald, 2008). The use of analytic memos helped the researcher to derive meaning from the data and identify themes. Analytic memos were recorded by the researcher throughout this process.

Data Analysis

Data analysis began after the first interview and developed throughout data collection. The transcripts were analyzed sequentially as each interview was obtained. Colaizzi's (1978) strategy for data analysis served as the framework for this research study. This was accomplished by first listening to each transcript within 24 hours of each discussion. When the transcripts were returned the researcher read and re-read each transcript to gain a general sense of the content of the interviews. The researcher listened to the interviews and compared to the transcribed data to validate accuracy and made corrections where necessary.

Codebook

NVivo11 software was used in data analysis of this study. NVivo11 software enabled the researcher to markup text, make notes electronically and code and re-code as often as needed (Rubin & Rubin, 2012). Computer programs allow the researcher to easily retrieve memos associated with codes, themes and transcribed interviews (Creswell, 2013). NVivo11 software facilitated concept mapping enabling the researcher to visualize the relationship among codes and themes (Creswell, 2013). The software did not analyze the data and determine codes/themes but assisted the researcher in the analysis process (Rubin & Rubin, 2012).

Significant statements were identified in each transcript. The researcher noted concept ideas in the column next to the significant statements. This iterative process was conducted until no new concepts emerged. Meanings were formulated from the significant statements (Shosha, 2010). Meanings were organized into clusters and ultimately into codes. Coding is the process of gathering the text into small categories of information and assigning a label to the code. The codes were developed into formulated meanings and ultimately identified the common themes that evolved from the verbatim transcripts. The use of member checking was used in data analysis to support the validity and credibility of the study findings. This was accomplished by follow-up e-mails/phone calls to discuss the summary of the findings and ask participants if they believed it described their experiences.

The interview transcripts, audio-recordings, field notes, journal, memos and analytic writing were reviewed by and discussed with the researcher's dissertation chairperson and/or committee members and outside reader to assure accuracy and meaningful data analysis. There was a wide range of valuable expertise provided by the committee members and outside reader. This committee's chairperson has taken care of individuals with dementia in her practice as a nurse practitioner. She also has experience conducting qualitative research. Another committee member teaches advanced qualitative research and has conducted research on other rare diseases. She has published on the topic of dementia. The third committee member has lectured extensively on topics related to dementia and its effect on afflicted individuals and their families. The outside reader is a content expert on the topic of dementia. She is a licensed, certified social worker, and a retired assistant professor in the School of Social Work at Molloy College. She

also served as the Coordinator of the Gerontology Program in her tenure as assistant professor. She has conducted research on the concept of denial and dementia caregivers.

Credibility and Validity in Qualitative Research

The credibility of a qualitative research study is dependent on robust validation strategies. The traditional approaches used to validate quantitative research are not applicable to the qualitative study design. There are many perspectives regarding the importance of validation in qualitative research including the definition of it, terms to describe it, and procedures for establishing it (Creswell, 2013, p. 244). A synthesis of validation perspectives in qualitative studies conducted by Whittemore, Chase, and Mandle (2001) revealed “four primary criteria: credibility (Are the results an accurate interpretation of the participant’s meaning?); authenticity (Are different voices heard?); criticality (Is there a critical appraisal of all aspects of the research?); and integrity (Are the investigators self-critical?) (Creswell, 2013, p. 248).”

In order to validate the credibility of this study the process of member checking was offered to each participant. Once the themes were developed and described, the participants were contacted to review the themes and to validate that the themes were congruent with their perspectives. They were also asked if there was anything they would like to add or delete. Changes were made based on participant feedback. Five of the participants responded to this request. Each of them identified with the themes and offered several comments. One of the participants had placed her husband in a long-term care facility and shared that she cried more now than when she was caring for her husband at home. One participant commented, “*This looks great.*” Another stated, “*I can definitely identify with most of the themes.*”

To enhance the trustworthiness and credibility of the study, the researcher used the process of bracketing. The researcher bracketed herself out of the study by discussing personal experiences concerning the phenomenon with her outside reader and reflecting on her perspectives through journaling (Creswell, 2013). Throughout the researcher's career as a registered nurse, she has cared for many older adults with dementia and their families, but she has had limited experience in caring for individuals with younger onset dementia. The researcher held aside those experiences in collecting and analyzing data to avoid any prior experiences from influencing the data analysis.

The researcher's assumptions included the expectation that significant others caring for a partner with younger onset dementia would be interested and willing to share the story of their experiences, and participants would answer questions honestly and to the best of their abilities.

Chapter Four: Findings

Introduction to Findings

This chapter will provide an overview of the descriptive demographics of the subjects interviewed for this study and their care recipients. This will include the process for recruitment of subjects. A detailed description of the participants will provide an introduction to their individual characteristics as perceived by the researcher. The tone and ambience of each interview will be depicted to provide a contextual framework for the reader. The process for data collection and data analysis will be clarified. Each participant selected or was assigned a pseudonym that will be used in reporting the findings to ensure that subject's confidentiality is maintained. This chapter will conclude with the emergent themes derived as described in Chapter three. The themes will be explored through the use of significant statements extracted from the transcribed interviews.

Study Sample

Recruitment for this study was initiated after IRB approval from Molloy College in April 2016. Permission was granted by the director of an agency serving individuals and families dealing with dementia in Westchester County to distribute copies of the invitational study flyer (Appendix A) at their main office. In addition, the recruitment flyer (Appendix A) was distributed at an annual meeting for caregivers and individuals with dementia held in Westchester County in May 2016. Recruitment was challenging and the first volunteer contacted this researcher by email several weeks after the flyer was distributed. It was disappointing to learn that the subject's wife had been living in a nursing home for five years and he did not meet

the criteria for participation in this study. This researcher expressed gratitude for his interest and reinforced the obligation to follow the inclusion criteria approved in the IRB application.

The second volunteer contacted this researcher by email from information from a flyer she received at the annual meeting for dementia caregivers in Westchester County. This volunteer met the inclusion criteria and an interview was arranged. After more than six weeks without contact from potential subjects, this researcher contacted an agency in Nassau County, New York that provides services to individuals with dementia and their families to request permission to distribute invitational flyers at their facility. Permission was granted. The inclusion criteria was discussed with the program coordinator who volunteered to personally deliver the flyer to individuals who she believed met the specific inclusion criteria. Three volunteers were recruited through this contact.

The next three volunteers were recruited through word of mouth by individuals who were aware of this study. Finally, an agency in Suffolk County serving individuals with dementia and their families was contacted to seek permission to distribute flyers, resulting in two additional study participants. All of the agencies contacted were extremely supportive of the objective of this study and verbalized their beliefs that it was important to understand the experience of significant others caring for a partner with younger onset dementia.

In summary, eleven subjects voluntarily agreed to participate in this study. Two were excluded; one because the spouse was living in a long term care facility for five years and the second volunteer decided her personal obligations interfered with being able to arrange to meet with this researcher. The final study consists of nine face-to-face interviews with significant

others caring for a partner with younger onset dementia. No further subjects were recruited as data saturation had been reached.

Data Collection

Contact with research participants was conducted using a combination of email and phone calls. A total of nine interviews were conducted from May 2016 to August 2016. All interviews were conducted face-to-face at a site selected by the research participants; six took place in their private homes and three were conducted in local libraries. The length of the interviews ranged from 39 to 102 minutes with a mean length of 65 minutes. Each interview began with introductions, an explanation of my role, and the objectives of our meeting. Each participant was asked for permission to record the interview.

A copy of the informed consent (Appendix B) was provided to each participant after this brief introduction. Each participant was allotted time to read the consent and then this researcher reviewed the consent with each one prior to signing. Participants were informed of their right to stop the interview and/or withdraw from the study at any time. All participants willingly signed the consent form and verbalized understanding of their rights as participants in this research study. An unsigned copy of the consent form was given to all participants so they could review and contact this researcher with any questions or concerns. After completing the informed consent process, each participant completed a demographic questionnaire (Appendix C).

All interviews were digitally recorded using an Olympus VN-702PC digital recorder. New batteries were inserted prior to each interview and additional batteries were on hand. The recorder was checked for proper functioning at the beginning of every interview. Each interview was initiated with the first prompt from the interview guide (Appendix D): *“Please tell me about*

your relationship (history as a couple) before your significant other was diagnosed with younger onset dementia. Please share what you feel comfortable sharing about intimacy, communication and other important aspects of your relationship.”

The flow of each interview was driven by the subjects’ responses and the additional questions on the interview guide were used intermittently to help keep the participants on topic when conversation strayed to other unrelated subjects or when there was a period of silence. The questions following the initial prompt were often re-worded to allow the subject greater latitude in their responses and avoid this researcher imposing her own understanding of the experience.

Following recommendations suggested by Rubin and Rubin (2012), this researcher asked permission to record notes during the interview process in order to capture details in addition to the audio-recorded transcript. All study participants agreed to note-taking by this researcher during the interview. Every interview ended with the question: *“Is there anything else that you would like to share?”* This frequently resulted in turning the recorder back on when participants thought of additional comments they would like to share.

Interviews ended when the subjects verbalized they had completed sharing their stories. Each participant was encouraged to call or email this researcher with any questions or concerns. The opportunity for a second interview was offered but no participants expressed the interest in a second interview. All of the participants expressed that there had been adequate time allotted to share their stories and did not feel a second interview was needed. All files including audio files, printed transcriptions, consents, demographic data forms and this researcher’s journal are stored in a locked cabinet and will be retained for three years after the study is complete.

Notes

According to Bazeley (2013), a project journal, field notes, and memoing assist the researcher in maintaining an accurate and reliable audit trail throughout the research process. A journal was initiated as soon as IRB approval was granted. This researcher recorded personal perceptions about the research process. Contact with all study volunteers was recorded including method (email or phone), any challenges in communication and initial impressions of our interactions. Only this researcher has access to this journal and it is kept locked in a file cabinet when not in use.

Field notes were taken during the interviews to record significant words or phrases, non-verbal cues, displays of emotion and the nature of interruptions that occurred in many of the interviews due to presence of family members in the house or phone calls that the subject responded to either by voice or text. The interruptions which occurred during several of the interviews impacted the flow of the conversation and it was important to record them to provide a reminder when the transcripts were read and analyzed. Additional notes were added after the interviews were transcribed while this researcher listened to the audio files of each interview.

Lastly, analytic memos documented in the journal provided an outlet for this researcher's reflections on what was learned from the data. Deriving meaning from the data through the use of analytic memos assisted this researcher in coding and the development of themes.

Characteristics of Research Participants

Demographic data was compiled from the demographic questionnaire (Appendix C) completed by each study participant. The descriptive statistics for the study participants for

gender, ethnicity, and number of years married, highest education level, employment status, and perceived financial status is provided in Table 1.

All of the research participants were women in heterosexual relationships, married to their current spouses ranging from 8 to 51 years. Five of the participants are working outside of the home, three are retired and one is on a leave of absence due to her caregiving responsibilities. The participants ranged in age from 49 to 73 years old with a mean age of 59 (n=8 as one participant left it blank). Educational levels varied as follows: three with master's degrees, one with a bachelor's degree and five with high school diplomas. Race/ethnicity selected was eight white and one black. Three of the participants stated they had serious financial concerns, one reported occasional financial worries and four selected secure and worry free.

Table 1

Participants' Characteristics

Participants	(n)	Percentage
Caregiver Gender	9	100%
Male	0	0%
Female	9	100%
Ethnicity/Race	9	100%
White	8	89%
Black	1	11%
Asian	0	0%
Hispanic	0	0%
Other	0	0%
# of Years Married	9	100%
Less than 1 year	0	0%
1-10 years	1	11%
11-20 years	1	11%
21- 30 years	4	44%
31- 40 years	2	22%
41- 50 years	1	11%
Highest Educational Level	9	100%
High School	5	56%
Bachelor's Degree	1	11%
Master's Degree /higher	3	33%
Employment Status	9	100%
Working	5	56%
Unemployed	0	0%
Retired	3	33%
On Disability	0	0%
Leave of Absence	1	11%
Financial Status	9	100%
Secure and worry-free	4	44%
Occasional concerns	2	22%
Serious financial concerns	3	33%

Demographics for living arrangements, number of children and type of relationships is provided in Table 2.

Table 2

Living Arrangements

Participants	(n)	Percentage
Number persons living in home	9	100%
2	3	33%
3	2	22%
4	2	22%
5	2	22%
Relationship of those living in home	9	100%
Children	6	67%
Couple	3	33%
Parents	0	0%
Other relatives	0	0%
Friends	0	0%
Number of Children	9	100%
0	1	11%
1	1	0%
2	2	22%
3	4	44%
4	0	0%
5	1	11%
Type of Children	9	100%
Mutual	6	67%
Combination	2	22%
None	1	11%
Close Relationships with those living in home	6	100%
Yes	6	67%
Not applicable	0	33%

The demographic information regarding care giving responsibilities is provided in Table 3

Table 3

Caregiving Responsibilities

Participants	(n)	Percentage
Caring Responsibilities	9	100
Personal Hygiene only	0	0%
Handling Finances only	0	0%
Managing medical care only	0	0%
Household chores only	0	0%
All except Personal Hygiene	5	56%
All	4	44%
Family/friends share caring responsibilities	9	100%
Yes	3	33%
No	6	67%
Family/friends share caring responsibilities: Relationship	9	100%
Friend	0	0%
None	6	67%
Adult children	3	33%

Four of the participants stated they were responsible for all aspects of caregiving; handling finances, managing medical care, household chores and assisting their spouse with personal hygiene. Five stated that were responsible for handling finances, managing medical care and household chores but not providing personal hygiene. Six of the participants stated that they

did not have assistance from family and friends with caregiving responsibilities; three reported sharing responsibilities with adult children.

Additional demographics concerning engagement in community activities and use of adult day care is provided in Table 4.

Table 4

Engagement with and use of Community Resources

Participants	(n)	Percentage
Engage in Community/Religious Activities	9	100%
Yes	5	56%
No	4	44%
What type of Community/Religious Activities	9	100%
Church	3	33%
Literature classes/museum	1	11%
Support group	5	55%
Not applicable	4	44%
Adult Day Care for Care Recipient	9	100%
Yes	5	56%
No	4	44%

Five participants stated their spouse attends an adult day care program. Five participants attended support groups for dementia caregivers. Four participants denied engaging in any outside activities primarily because of time constraints.

Demographic data about the significant others with younger onset dementia is provided in Table 5. The average age of the spouse with younger onset dementia was 62, ranging from 55 to 73 years old. The average age at time of diagnosis was 57 years old, ranging from 52 to 64 years old. The types of dementia reported by the participants were: Alzheimer's disease (56%), frontotemporal dementia (11%), and three of the afflicted significant others had never received a final diagnosis for the cause of their dementia (33%).

Table 5

Characteristics of Younger Onset Dementia Partners

Partners with YOD	(n)	Percentage
Gender	9	100%
Male	9	100%
Female	0	0%
Ethnicity/Race	9	100%
White	8	89%
Black	1	11%
Asian	0	0%
Hispanic	0	0%
Type of Dementia	9	100%
Alzheimer's	5	56%
Frontotemporal Dementia	1	11%
Unknown	3	33%
Other Medical Conditions	9	100%
Heart condition	2	22%
Obesity	2	22%
Alcoholism	2	22%
Back surgery	1	11%
High BP	1	11%
Highest Educational Level	9	100%
High School	4	44%
Bachelor's Degree	3	33%
Master's Degree /higher	2	22%

Partners with YOD	(n)	Percentage
Employment Status	9	100%
Working	0	0%
Retired	5	56%
On Disability	4	44%
Occupation	9	100%
Attorney	1	11%
EEO specialist	1	11%
Firefighter	2	22%
Insurance	1	11%
Sales	1	11%
Sanitation	1	11%
Not answered	1	11%

According to Creswell (2013, p. 184), qualitative researchers use “detailed description” to provide the context of the setting of the person, place or event. Detailed description serves as the basis for coding and developing themes. It also enables the researcher to share the framework for the interpretation of data in the context of the researcher’s own views or perspectives (Creswell, 2013). The following description of each of the study participants serves to enhance the reader’s understanding of the data analysis. Pseudonyms are used for each of the nine subjects to ensure confidentiality.

Description of Participants

Following is a detailed description of each of the participants in this study.

Patty

Patty is a 73 year old retired physical therapist, married to her husband for 51 years. She is the oldest of the nine study participants. They have three adult children who are married, with a total of seven grandchildren. Only one of their children lives locally but she speaks to all of her

children frequently on the phone. The interview took place in the couple's apartment on a sunny spring day in May. Patty greeted me warmly and stated "*I've been looking forward to meeting you.*" She appeared younger than she sounded on the telephone. Dressed in a brightly colored print shirt and crop pants, her outfit matched the smile on her face as she began to share her story. Patty was eager to talk and the dialogue flowed easily throughout our interview. The apartment was bright with large open windows and a fan was blowing since the day was warm.

Patty described her early relationship with her husband as "*very close, we met when we were 19, sophomores in college.*" She described their relationship as "*very warm and affectionate.*" Patty was eager to talk about how dementia has affected their lives as a couple and the impact on their social lives. She frequently referenced her experience as a physical therapist as giving her added advantage to understanding what was happening. Patty referred to this as "*being in the field.*" Her clinical background played a role in her quest for participation in multiple clinical trials. During the interview, she frequently laughed, expressing an emotion that often did not match the serious nature of her response. She became teary-eyed several times and appeared to be trying to keep her emotions under control. Her hands revealed mild tremors and she kept them crossed on her lap as we spoke. She voiced concerns about her own health and pointed to her swollen feet, stating, "*I have gained thirty pounds in the past six months.*" She was articulate in her responses and never at a loss for words. She expressed her reason for participating in the study was to "*make things better in the future for others.*"

At the conclusion of our interview, she asked for my opinion of the space she might use if she needed to engage live-in help to assist her in caring for her husband. Patty was very practical in her explanation of how she was anticipating her needs and the needs of her husband as his

symptoms progress. She stated she has seen a marked decline in the last six months. Patty portrayed many emotions during the interview, from crying to laughing and then assuming a serious business-like demeanor. She was very engaged and the conversation flowed easily.

Sally

Sally is a 56 year old woman, married to her husband for 32 years. She works as a hairdresser part-time. The couple has four children but only three are currently living at home. I arrived about 20 minutes early for my appointment to meet Sally at her private home. I called to let her know that I was there and asked if she was available. She invited me to come in. When she answered the door and let me in, her husband and daughter were in the living room. Her husband seemed pleasant but it was hard to determine if he understood why I was there. She invited me to sit at the kitchen table. Since it was an open floor plan, there was no privacy provided to conduct the interview. I asked if this was still a good time for her and reinforced that the interview was only for her. She said it was fine, although the situation felt quite awkward. Sally asked her daughter if she could take her father shopping at Best Buy but her daughter stated she had planned on going for a bike ride. I offered to come back at a more convenient time but Sally assured me it would be okay, her husband could take a walk with their dog since it was a mild, sunny summer day. Her husband seemed agreeable to that arrangement and her daughter took off for her bike ride.

Sally was dressed casually in jeans and a t-shirt. She did not talk easily and it took several prompts to elicit an on-going dialogue. My initial impression was confusion about her interest in participating in the study as it was challenging to get her to say more than a few sentences to each of my prompts. We had to stop and start the interview three times as her

husband kept coming in and out of the house. Although, I offered again to come back at another time, she insisted that we could continue.

Sally spoke in a soft voice and made several comments about her husband's temper. This was such a strong theme throughout the interview that I was compelled to ask her if she was concerned for her own safety. She stated her husband "*just yelled a lot*" and she was "*done*" but she was not fearful for her own safety. She stated she was "*tired*" and rarely smiled during the interview. She was very focused on what may have caused her husband's dementia and proposed several possibilities that she has considered.

Sally stated she was very unhappy with herself as she has not been able to exercise and has gained weight. In fact she stated, "*I hate being fat. Hate, hate, hate, hate that!*" She did not appear to be more than 10 pounds over her ideal weight but this was a very strong concern for her. It was challenging to get more than short and concise answers to my prompts. The interview ended abruptly when Sally seemed to have nothing more to say. My overall impression was that Sally was quite overwhelmed by her current situation and was searching for ways to cope. I provided referral information about adult day care programs and support groups to her at the conclusion of our interview.

Woody

Woody is a 62 year old retired administrator, married to her husband for 35 years. The couple has two children. Their daughter is still living at home and is very involved in assisting Woody in the care of her father. Since I was stuck in traffic, I called Woody to let her know I may be a few minutes late. When I arrived in front of her home, she immediately waved for me to park in front of her house and came down to the gate to greet me. From the moment we met,

Woody was warm and welcoming and very much in command of the situation. It was a warm summer day and the air conditioner running in her living room provided some challenges in ensuring that the dialogue was audible.

Woody was passionate in describing her feelings for her husband and spoke vehemently about her struggles to help him maintain his “*dignity*” especially when interacting with healthcare professionals. Her face lit up when she spoke lovingly about the type of man her husband was and conveyed feelings that focused on how things used to be. Once Woody started to talk, her stories were detailed chronicles of the couple’s journey from the beginning of their relationship, the onset of dementia, and the current state of affairs. Woody talked non-stop with very few breaks in the conversation. She spoke with great passion, smiled frequently, and cried when she talked about how hard it was for both her and her husband. She used the word “*hard*” many times throughout the interview.

Woody expressed the hope that this study may help others in the same situation. She introduced me to her daughter and asked if I would like to ask her a few questions. I expressed gratitude for the offer but I explained that this study was limited to significant others caring for a partner with younger onset dementia. She was very appreciative of the opportunity to tell her story and stated she looked forward to hearing about the results.

Rose

Rose is a 51 year old retired flight attendant, married to her husband for 14 years. This is a second marriage for both. Rose has two sons from her first marriage and her husband has a daughter from his first marriage. Rose and I met at a public library conference room near her home. She told me her husband knew about the interview but she preferred to meet in a public

place. I arranged to use the room in advance and it was very comfortable and conducive to the interview process. Rose arrived promptly and I met her in the library lobby. She was dressed casually on this warm summer day and walked in with an air of confidence.

Rose was very eager to talk and shared her struggles with her husband's alcoholism and discovery of infidelity. Although Rose talked frequently about her commitment to her marriage, she never used the word love in describing her relationship with her husband. She repeatedly gave examples of incidents in which she told her husband and members of his family that, "*I can leave at any time.*" She expressed feeling "*angry*" when relaying her story and yet was quite emotional at times when talking about the changes occurring in her husband and their relationship.

Rose conveyed a strong sense of confidence and independence. Her take charge personality and preference for organization and control was a thread throughout the interview. Her work experience and work ethic appear to influence how she manages her personal life. She spoke easily about her need for activities for self-care and described her practice of taking short breaks from caregiving as a coping strategy.

Rose displayed a wide range of emotions throughout the interview. One of her most poignant comments was, "*this doesn't happen in a vacuum.*" The flow of conversation was smooth and there was no hesitation when a prompt was provided. Given the personal nature and sensitivity of the interview topics, I was quite surprised that Rose shared easily with such candor. She stated she had been looking forward to the interview and had started to think about what she wanted to talk about in advance. When the interview ended, it felt as if two friends had been discussing life as they know it.

Doris

Doris is 49 years old and the youngest of the participants in the study. She is currently on a leave of absence from her job as a personal executive assistant. Doris is a very attractive woman, dressed stylishly in floral Bermuda shorts and a crisp white cotton blouse. Her makeup and hair were impeccable and she approached the interview in a very business-like manner. Although she and her husband grew up in the same town and went to high school together they had only been married for 8 years at the time of the interview. The couple does not have any children.

The interview took place in their high rise condominium in a beautiful location on the South Shore of Long Island overlooking the ocean. This idyllic location was in sharp contrast to the story Doris shared about her experience caring for her husband with younger onset dementia. They had moved to Florida several years ago but were encouraged by family and friends to come back to their hometown in New York. However, throughout the interview, Doris stated that she couldn't wait to go back to Florida because things were much easier there. Her husband had health issues very early in their marriage requiring surgery and rehabilitation. Shortly thereafter, the symptoms of dementia began. Doris has been in a caregiver role since the second year of their eight year marriage.

There were no tears displayed as she shared heart-wrenching details about events that may have warranted displays of emotion. She used analogies such as taking care of her husband was like taking care of a *“colicky two year old who speaks Russian.”* It was difficult for her to sit still. We talked in her home office; she had her computer turned on and her cell phone in her hand, frequently responding to messages intermittently during our time together. She stated in a

monotone voice, *“I try not to feel.”* She relayed examples of how she is a strong advocate for him especially when interacting with healthcare providers but she states she feels like *“I am the enemy.”* Her statements conveyed her ability to understand the clinical language and an overarching thread of frustration and powerlessness since they have not been given a definitive diagnosis. In spite of a significant investment of time, money, and personal energy seeking the expertise of multiple healthcare providers, the cause of her husband’s rapidly progressing dementia is unknown. Doris depicted the lack of support from family and friends, as well as unsatisfactory answers from health care professionals.

Doris contacted me five months after our interview to tell me that she had placed her husband in a long term care facility. She is still searching for answers and is eager to hear about the final analysis of this study.

Minnie

Minnie is 52 years old and married to her husband for 28 years. She works full time in sales and has a very demanding career. Scheduling an interview took several attempts and we finally met at a golf course where she was participating in a fundraising event. She stated she would have some free time before the dinner. I met Minnie in the lobby. She was dressed in shorts and a tee shirt on this hot sunny day. She greeted me with a smile and I anticipated that we would go to a private room. It was awkward when she guided me into the dining room. The tables were set for dinner and there were guests and employees walking in and out of the room. When she guided me to a table in the corner of the room I asked her if she was comfortable to talk in this very open environment. She stated it was fine with her. Although, the music was

playing rather loudly and the wait staff were opening and closing doors, we proceeded with the interview.

Despite the lack of privacy, Minnie responded to my prompts readily but her answers were often brief and it was challenging to elicit more details of her experience. As a result, this interview was the shortest of the nine interviews and lasted only 39 minutes. She stated that she was relieved when her husband was diagnosed with AD as she initially thought it was a problem with their relationship and shared, *“I was afraid he was cheating on me or had given up on our relationship.”*

Minnie spoke with limited displays of emotion of the impact of her husband’s diagnosis on their two sons who are both living in their family home. She spoke of her marital relationship as a *“strong partnership.”* She shared that she spends a lot of time at work. Minnie admitted, *“I don’t like to be together. It feels like I’m with a five year old. I guess I avoid home.”* One of her final comments was *“it feels like a storm is coming. How long do I have?”* Contrary to her calm voice, this comment provided insight into her fears. When the interview was over, Minnie needed to get something from her car and we walked out to the parking lot together. Ironically, we had both just bought the same make and color car and it seemed to end the meeting on a note of a sort of camaraderie.

Sunny

Sunny is a 56 year old healthcare professional, married to her husband for 30 years. They have three children; one is still living at home and the other two children live independently. This interview took place on a sunny, summer morning. I arrived at their home and a man dressed in sweatpants and a tee shirt answered the door. He was friendly and smiled when I told

him I was there to meet with Sunny. He closed the door and I heard him calling her name as I patiently waited outside.

Sunny arrived dressed in business casual pants and blouse as I expected since we were meeting this morning before she was going to her full-time job as a substance abuse counselor. She happily invited me in and we sat down at her kitchen table. Sunny explained that the man who answered the door was her husband. He retreated to another room in the house and I did not see him again.

Sunny was calmed, relaxed, and eager to share her story. Sunny spoke of her husband lovingly and described their journey in a matter of fact, confident manner. She expressed the benefit of her clinical knowledge in helping her to understand what was happening to her husband.

The dialogue flowed easily as Sunny described her journey from the time she noticed changes in her husband to a diagnosis of Alzheimer's disease to the current situation. Her husband's loss of employment has had a significant impact on their financial situation. Sunny spoke with a tone of melancholy when she expressed that her attorney had recommended the couple sell their family home. She looked nostalgically around at the meticulously decorated rooms. Although she communicated in a pragmatic manner regarding her family's challenging financial troubles, she stated, "*We'll do that [sell the family's home] when it's necessary.*"

Sunny described her oldest son's significant mental health issues which had consumed her attention and delayed her focus on the changes that were occurring in her husband. She answered questions thoughtfully, frequently smiling and laughing at appropriate times.

Sunny spoke passionately about her work and her co-workers as being a critical support system. As she was talking about sexual intimacy, her son walked into the kitchen and we had to stop and move into the living room. The rooms were separated by a half-wall and I was concerned about the lack of privacy and the interruption in the momentum of our discussion. But Sunny resumed comfortably when we got re-situated, and I restarted the digital voice recorder. The interview continued as Sunny described her life and how she copes day-to-day. She depicted a demeanor of control and self-assuredness while conveying a sense of warmth and love. Sunny described the uncertainty of the future but depicted a woman capable of handling what lies ahead.

Jane

Jane did not disclose her age on the demographic questionnaire but appeared to be 50 -55 years old. She has been married to her husband for 29 years and they have three children, two are still living at home. We met at a public library in her home town. Jane entered the room walking briskly and greeted me with a warm smile. She was dressed in cotton black pants and a print blouse on this warm summer day. When we started the interview she seemed very distracted with messages and calls on her cell phone. I asked if she needed to reschedule but she stated we could proceed. We did have to stop and start several times due to her need to answer the phone. This pattern validated what Jane focused on quite a bit during our interview; *“everyone depends on me”* and *“I have no time for myself.”*

Jane had been a stay at home mother until her husband lost his job due to the symptoms of younger onset dementia. This resulted in Jane going back to the workforce without updated

skills and she struggled to find employment to help support her family. With financial support from a family member, she was able to get training and got a job as a medical secretary.

Jane depicted a sense of concern for her husband while her story described a relationship in which her husband spent long hours at work and there were few examples of closeness in their relationship before the onset of dementia. Jane stressed her concern for her children and her fear, *“What if something happens to me, what would happen to my children?”*

Jane was forthcoming with her responses and engaged in the interview despite the intermittent interruptions from her phone. Her quest for answers about why this has happened (her husband’s dementia) and what caused the dementia was repeated several times during our conversation. Jane radiated energy and a sense that she would persevere in the face of challenges. However, her facial expressions frequently conveyed worry and concern.

Lynne

Lynne is a 56 yr. old woman, married to her husband for 27 years. She works as a legal secretary. The couple has one daughter who is still living at home. We met on a hot summer day at Lynne’s house. Lynne is a petite woman with medium length straight blonde hair. She was dressed in pale blue shorts and a white tee shirt. She spoke softly and I often had to strain to hear her speak. Lynne got up from her chair several times during the interview stating, *“I can’t sit for long periods of time. I need to move around.”* Lynne and her family had just moved to this house because they couldn’t afford to maintain the house they had been living in. Lynne’s daughter walked in and out of the adjacent room during the interview. She did not attempt to engage in our conversation but she stayed within hearing distance for a few minutes. This did not seem to bother Lynne and did not affect her engagement in the interview.

Once the conversation began to flow, Lynne answered hesitantly but responded to the prompts thoroughly. It was hard to tell if she was thinking about her response or if she was thinking personal thoughts that she had not decided to share. Lynne told her story methodically and revealed the significant changes in their lives because of her husband's younger onset dementia. Lynne's demeanor conveyed an aura of vulnerability. Her interest in participating in the study seemed to be motivated by her search to understand about the disease and about how she was going to manage its impact on the lives of her family and herself. Lynne has been dealing with her husband's dementia for ten years, the longest time period of all nine participants.

Summary

Each of the nine women who participated in this study had a unique story to tell. The emerging themes will illuminate the lived experience of these study participants caring for a partner with younger onset dementia. Despite differences in my interactions with each of the participants, what was overpoweringly evident was their needs to have someone listen to their stories. The next section will describe the process of how the transcripts were analyzed.

Data Analysis

The iterative process of analyzing the data for this study began with listening to each of the recorded interviews within 24 hours of each interview. This approach facilitated accurate recall of the details of the subject's non-verbal mannerisms and gestures. The first listening experience was accompanied by reflective notes written in this researcher's journal. As each transcribed interview was returned to this researcher, the transcript was read while listening to

the digital audio-recording. Corrections were made to each written transcript, when words were inaccurately transcribed or did not add to the dialogue such as um, ah and uh huh.

NVivo 11 software was used to organize and manage the data for coding and development of themes. The transcripts were imported into the NVivo software program after the corrections were made on the electronically stored documents. Since the interviews spanned from May 19 to August 13 2016, entry into NVivo was not complete until the last interview was conducted and transcribed.

Coding was initiated as soon as each interview was transcribed. Colaizzi's (1978) strategy for data analysis served as the framework for this research study. Polit and Beck (2012) outlined Colaizzi's strategy as one of three analytic approaches appropriate for data analysis in qualitative studies. The transcribed interviews were read and re-read to acquire a feeling for them. An additional step conducted by this researcher was augmenting reading with listening to the audio-recording of each interview. Significant statements were selected and organized into categories that spelled out the meaning of each statement. The next step was aggregating the categories into clusters of themes. Each theme was then reviewed to confirm the appropriate placement of each sub-theme. Several statements appeared to fit into more than one theme. Each was thoroughly reviewed and placed in the theme that appeared to be the best fit. The identification of the emerging themes was completed after a thorough review of the placement of significant statements from all transcribed interviews into categories in the NVivo program. The final results were collated to provide a comprehensive description of the phenomenon of this study.

Written transcripts as well as the digitally recorded audio-files were sent to this researcher's dissertation chairperson and content expert serving as an outside reader. Several debriefing sessions were held with this researcher and her dissertation chairperson to review impressions of each interview and to discuss significant statements. In addition, separate debriefing sessions were conducted with the content expert to corroborate the findings.

Additional notes were entered in this researcher's journal to record ideas and suggestions discussed at the debriefing sessions. Sessions were held until all interviews had been discussed and significant statements were identified to support the coding and ultimate discovery of the emerging themes. This process yielded the extraction of 310 significant statements from the 584 minutes of audio-recorded narratives. The debriefing sessions provided an opportunity to validate the findings. The findings were sent to all participants for their feedback.

The next section will present the themes that were identified by using the process of data analysis described. The themes that emerged were: (1) The Way it was Before Dementia; (2) A Maze of Uncertainty; (3) A Kaleidoscope of Feelings; (4) Shattered Dreams/Expectations; (5) A Solitary Journey; (6) The Struggle to Survive; and (7) Navigating Day-to-Day. Selected excerpts from the interview transcripts will be used to illustrate the meaning of the themes as the subjects described their lived experience as a significant other caring for a partner with younger onset dementia.

Emerging Themes

The analysis of the data resulted in the identification of seven themes. The themes illustrate the meaning of the phenomenon of this study as expressed by the participants. The

themes describe the complexities of living with a partner with younger onset dementia and the impact on the couples' relationships as well as the effect on their families and friends.

Theme 1: The Way It Was Before Dementia

Every interview began with a prompt designed to gather information about the couple's relationship before the onset of younger onset dementia. The purpose was to gain an understanding of the couple's interpersonal dynamics prior to the onset of dementia. There was variation in how each participant described their relationship in the beginning of their marriages; all of the subjects were married. Regardless of the type of relationship described, each of the nine subjects explained how things were different now.

Patty and her husband were college sweethearts and married during their sophomore year of college. She described her husband as *fun loving* and repeated the word *fun* several times as she talked about her husband's personality before the onset of dementia. She spoke lovingly of how others enjoyed being in his company, sharing "*He was the kind of person that if I brought him to work, everybody would remember that he was there. And everybody always has a funny joke about him but nobody dislikes him.*" Patty talked about their relationship in a soft, wistful voice when she recalled their early years together:

It was a warm and affectionate relationship. When I had difficulty, when I reached the age my mother died at, I went to a psychologist for six months. And when I came home from the psychologist, I would tell him everything. She (the psychologist) said that was extraordinary. And I've had that kind of relationship that's very open, so that when I came home from doing something, I, even to this day, first thing I'd want to do is tell him (referring to her husband).

Lynne recalled the beginning of the couple's relationship, in a melancholy voice, *"We had a very exciting fun existence at that point. Two and a half years in we decided to get married."*

Woody confidently and passionately stated, *"We had a very good relationship. We were very family oriented and did family things. He was a family guy, he loved his family. And we had a very, sweet, loving relationship and very intimate. It was very nice."*

Rose smiled as she stated, *"I would say we had a very good relationship. We enjoyed each other's company very much. We had a different lifestyle as this was the second marriage for both of us. So we dated for a long time, a proper Irish courtship."* She went on to describe how they negotiated time alone when her sons were young:

We were able to arrange our schedules to have two or three days off, so between the two of us, we had plenty of time to be together without the kids around. I kept it that way with my two sons. I didn't feel like he should be at my house overnight.

Doris spoke enthusiastically about the beginning of the couple's relationship and their long history prior to getting married, stating:

He went to school with my sister; I've known him my whole life. I came home for a family vacation in August and met him and we instantly hit it off and I relocated probably four months later. We were engaged very quickly and married the following year, which was, we just celebrated our eight years (wedding anniversary) last week, actually.

Sunny talked in an upbeat tone about her relationship sharing, *"We have been married for over thirty years, and I'd say that we had a really good relationship before this happened. We have raised three children together and we're definitely partners in that. He's a great father."*

Minnie spoke in a neutral, business-like tone of voice about the couple's early days:

So history was always a very strong partnership and we both had very active careers. He was at the height of his career and I was at the height of my career and we were

continuously, pursuing more interests in the line of work. Although, we'd be in touch pretty much all day.

Not all of the participants recalled the beginning of their relationship in such a positive light. When Jane was asked to describe the couple's relationship before dementia, she expressed the difficulties of long work hours and little time together as a couple. Jane explained that the couple rarely had time together and her husband was generally too tired for social outings:

It was kind of on the stressful side. He was a salesman on the road and he wouldn't get home until seven, eight o'clock at night. So needless to say with three children, our relationship kind of went very separate ways because he was never there. When he was there he was exhausted.

In responding to a question about mutual interests that she may have shared with her husband, Jane replied, "*We never really had a great social life because he was always working and then he was exhausted.*"

Rose spoke about her early concerns regarding her husband's drinking habits. She recalled, "*I knew when I met him that he was a drinker. I liked to have a cocktail too, don't get me wrong. But I remember thinking after the first date, he drinks more than I like.*"

Sally spoke in short brief sentences as she described the couple's early relationship. She stated, "*He got mad- gets mad easily. He, just, he was just kind of like, you agree with him or you're against him. He is kind of set in his ways, difficult.*" Sally continued her description of her husband's behavior before the onset of dementia with examples of criticism of her behavior:

I used to think that he couldn't control it and my friend was like but he doesn't do it in front of other people does he? I'm like no. It's always when we get in the car after we're leaving, I find out everything I did wrong. Everything I said wrong, all the way home. But she's like, well then, he can control it because he knows he can't do it in front of other people.

Although Doris had originally spoken positively about the couple's early relationship, she smoothly transitioned to talking about early events that had a negative impact on the couple's relationship;

So it was wonderful, at first, because he just retired from being a fireman after twenty-two years, and then he ended up with back issues. So literally, a year and a half after we got married, he ended up having to go and get surgery on his back. So it was a caregiver role (for her) prior to this happening (referring to the onset of dementia).

In spite of the diverse descriptions of the early relationships conveyed by the nine study participants, coding illuminated the dominant theme of uncertainty. The following section includes a description of the meanings in the words of the participants.

Theme 2: A Maze of Uncertainty

The overarching theme of uncertainty emerged as the participants expressed statements which conveyed the influence of uncertainty across the trajectory of their experience of living with a partner with younger onset dementia. Uncertainty was ubiquitous in the stories shared by each of the nine participants in this study. The theme of uncertainty was depicted in the following subthemes: (1) why is this happening, (2) getting a diagnosis, (3) interactions with healthcare providers, and (4) things are constantly changing. Excerpts from the transcripts will be used to depict the meaning conveyed by the participants in each of the sub-themes.

Why is this happening?

Beginning changes in the partner with younger onset dementia were attributed by some participants as being linked to issues of drug and alcohol use. Lynne described her first impression of her husband's behavioral deviations as, *"I took it as disinterest. M... liked to*

smoke some marijuana so I mean, I thought maybe he was smoking more than he originally was.” She went on to describe her perceptions of what was happening when she reflected back on behavior changes prior to a significant event. Her husband experienced an episode of syncope that required hospitalization. After this event she began to think about the subtle changes in her husband’s behavior that she had attributed to stress and/or problems in their relationship. Lynne recalled:

Yeah, so up until ten years ago he was very healthy, no issues. I look back a bit now and I do notice, when I think about it in hindsight, I realize that probably six months before this incident happened, he was what I thought was disinterested. I thought that he was you know, having a lot on his mind.

Rose talked about her husband’s drinking and how she believed that her husband’s behavior was affected by his alcohol abuse. It was hard for her to distinguish his behavioral changes as something different. Rose stated:

So that was the beginning and I think when you live with a person too, also because of the alcohol part too, you slowly, these things happen and it sort of becomes like a new normal. I noticed his gait, his walking was like what? What is this kind of wobbling? The alcohol, the alcohol, the alcohol, that was a big problem. That really –that was the whole problem as far as I was concerned.

In some cases accidents and medical events were cited as possible causes of variations in behavior. Sally recalled an accident that she believed had triggered behavioral changes in her husband. She went on to say:

He was a sanitation worker and drove a garbage truck... He did get a hit in the head, a hard hit in the head that he ended up in the hospital in 2012, I think. And I wonder if that was it. Somebody had the garbage can on a high pile of ice, snowy ice and he fell, he slid and he almost went under the truck but his head hit the truck. So I wonder if that accelerated something.

Doris spoke about her husband's back surgery and the changes that occurred during his recovery. She stated, *"I always thought that maybe the back surgery had something to do with it; anesthesia, a spinal leak."* Doris relayed her confusion and frustration as she spoke about trying to figure out what was happening. She recalled thinking:

Why is it all of a sudden, you have a person who a week ago was fine, now it stinks to high heaven and doesn't know what happened. Is it sleep deprivation? What is it? Is it the moon? The full moon?

Minnie described concerns about problems with the couple's relationship and her belief that her husband may be having an affair. She spoke about her feelings at that time, sharing:

And it was very confusing to both of us because he didn't, we didn't know what was going on. And you know this (younger onset dementia) was not on our radar screen at all. And so we talked a lot about, a lot of questions being like, as far as what was going on with him. Was it a mid-life crisis? Was it like did he just stop caring? So it was a very emotional time for the two of us over that time period because he would not be able to describe what was going on.

Getting a diagnosis

The quest to find out what was causing the behavioral changes in their partner with younger onset dementia revealed challenges poignantly described by each of the participants. Although each of the experiences was unique, the difficulty in getting a diagnosis was a commonality for all. Despite recognition of a problem it was difficult to get definitive answers in their quest for information.

Although Jane, persisted in her pursuit of an answer, it took many years to find out what was wrong. Her husband's healthcare provider ignored her concerns, causing her to question her own perceptions. Jane shared:

And then, I questioned the doctor constantly because I always felt that there was something wrong, that he didn't understand stuff and she always said, "Oh I don't think

he has Alzheimer's, I think it's a processing problem." I don't know if she put two- and- two together that frontotemporal (dementia) is a processing problem. So after many years of questioning it and him having physicals and she saying, "I just started to think he had a processing problem.

Sally explained the long road to getting a diagnosis of Alzheimer's disease. She described multiple visits to their doctor, an exhaustive battery of tests, and how they finally received a diagnosis:

He had many tests. And everything was negative, negative, negative. Until the last one, the doctor said he's just too young for this. I'm going to prescribe him, a PET scan and that's when he called me at work and said he has Alzheimer's.

Sally described her reluctance to accept the testing results. She expressed that her husband's lack of computer skills and the time of day may have skewed the results. But according to Sally:

It was later in the day the last time too that's what I said when he called and said he got worse, moderately he said it's to be expected. I said, "Well, you know, he's not good on the computer because it's with a mouse, he's never even done that.

Lynne talked about her husband's episode of syncope and how her husband's behavior, especially his short-term memory, seemed to be affected:

And they put him on telemetry and nothing was happening, everything seemed to be fine and then about two days in, he flat-lined for about 17 seconds. During the course of that two days though I noticed that his short term memory had been sort of wiped out and I was told that it was a lack of oxygen to his brain that it would probably come back once everything -- they put a pacemaker in.

Lynne continued her story sharing "All kinds of blood work was done, everything was fine. First it was maybe he's depressed. They gave him medication for depression. I had never known him to be depressed, but you never know, you know?"

Finally, Lynne described the conclusive end to the journey to getting a diagnosis, stating:

So, we went to Columbia to the Memory Disorder Clinic. I got him an appointment there. They did - they ran a battery of tests, they felt that it was Alzheimer's as well.

They didn't have a definitive, but they felt that, you know, so when I say we got a diagnosis we never got an actual diagnosis for many, many years. Probably until two years ago actually somebody actually said this is younger onset Alzheimer's.

Despite finally getting an answer, Lynne stated, “*I was not accepting that it was an Alzheimer's thing.*” It was hard for her to reconcile the diagnosis with her husband's young age.

Doris described a relentless journey to find out what was wrong but they came up with more questions than answers.

I mean the - the biggest problem I had is they don't know if it really was a stroke. They don't know if it was some sort of phenomenon episode that happened with, they're thinking the retirement, back surgery, hurricane, the move, the stress of it all just (deep sigh). So I've been dealing with second opinions and third opinions and I've been everywhere in the country and globally just to try to get an answer because he's really more of a dementia without, it's like dementia with unknown cause. You think a man without a country that's kind of what they call him.

Doris continued to explain the feedback from the most recent medical consultation in her quest to find the cause of her husband's dementia. “*And the loss of oxygen, that's what the doctors told me up in Massachusetts General last week, he thinks it's mostly due to the loss of oxygen*”.

Woody described her experience in her initial search for answers, stating:

So he went to the doctor. And the doctor had sent him to a neurologist and the neurologist asked him a couple questions and he's like oh good news, bad news, I think you have sleep apnea and it's treatable. He had gone to the doctor prior to that the time about going before he went to the neurologist and she gave him some time off because she felt maybe it was stress, and that was causing the issues.

Woody continued to express the unique challenges she and her husband experienced. Co-morbidities such as obesity and sleep apnea complicated the path to obtaining a diagnosis.

Woody shared that:

And because he is such a big guy, he's like six seven, he weighs over 400 pounds they did not have any machines that would fit him and I mean if he was frustrated, I was

frustrated because we were constantly going to places and they were like I'm sorry we cannot handle him. We can't do it.

Woody described a journey of perseverance to a definitive diagnosis:

I was like I need to find out something and I went to, someone who suggested that he see a neuropsychologist, and I fought with my insurance and I got him the okay. And I found a lady who we met with and she tested him. And she said yes, he has early onset Alzheimer's. She said, you know, get him in a day program and I advise you all as a family that, to do some things while you can.

Her bittersweet reaction is captured as she stated, *"I said you know, cancer is bad, I said but you can be in remission and he (a relative with cancer) is in remission but you don't go into remission in Alzheimer's."*

Rose shared the realization that her husband's behavioral changes were not related to alcohol abuse. She voiced that this was shocking and confusing, stating:

But, once he stopped drinking, you know, quote, unquote. Well I said M., we have got to go a neurologist, there's something, definitely something wrong here. So we did, we went to a neurologist, he had all the testing and they diagnosed him with mild cognitive impairment. I kept on saying, you know, what does that mean? And I'd look and everything's so vague.

Rose continued to describe the testing process and revelations about her own behavior in response to her husband's cognitive changes:

So but the first time that we were in the office together, she did some minor, you know, medical things and she said, I'm going to ask M. questions and she didn't want me -- she said, "you're not -- you're not to speak. Just -- just listen". And she talked to him and asked him questions. I was in shock. I was stunned at how little he knew. I didn't realize how much -- how often I fill in.

Sunny depicted her husband's perception that everything was fine. She later found out that his secretary had noticed changes and that she had to redo some of his computer entries.

So then he did the cognitive testing. And meanwhile the doctor's saying to him, you know, how you doing at work? How are things, you know? And he'd - my husband, you

know, the typical deny -- I'm fine, everything's fine. Really? And, so one day I talked to his secretary and she said, no things are not fine. You know, I've been covering for him. I have to do a lot of things over. I have to have him do them over and you know he can't work the computer anymore; he's having difficulty with that.

Sunny revealed her shock when the doctor revealed the results of the cognitive tests. It was so hard for her to believe; she asked her husband to draw a clock at home and realized he could not accurately draw the time. Sunny shared:

I'll never forget when the doctor said to me, um, so yeah, we were looking at his results and, you know, he didn't do so well on this half and he was sitting there so I think he was trying to he goes, but when we had him draw a clock he couldn't draw it. And I remember going what? What do you mean he can't draw and of course now I - I know that's a very, you know, indicative sign so I asked him when we got home that night I said to him, I want you to draw me a clock because I couldn't believe it. I couldn't believe he couldn't draw a clock. And of course he could draw the clock; he just couldn't do the time.

Patty shared her reaction to receiving the diagnosis of Alzheimer's disease stating "You know, you can't really hear - you don't really hear everything they're saying because you're blocking out a lot because you just can't bear it so it is, it's very hard to hear."

Minnie connected her husband's unsuccessful attempts to find employment as a mitigating factor in the pursuit of a diagnosis, sharing:

And so he went to bus driving school and again, you know, secured the job, very reliable, shows up, very pleasant personality and demeanor, but he couldn't, he could never pass the bus driving test because of the different processes that are involved to do air brakes and it's not like driving a car. So we just kind of pushed and pushed for like a reason of what was going on and then we got the diagnosis in like 2012.

Minnie continued as she expressed a surprising reaction to a diagnosis of dementia:

After that it was a big relief, you know? Relationship was - was strong then". She stated in a concerned voice. What's the best, treatment? There is no treatment other than, you know, he was on Aricept for a while by then, which doesn't do anything.

Interactions with healthcare providers

Dealing with healthcare providers and healthcare systems emerged as a significant cause of the uncertainty expressed by the participants in this study. The causes of uncertainty were cited as, knowledge deficits regarding dementia in middle-aged individuals, ignoring the participants' feedback about changes in their partners, lack of interpersonal skills, and lack of guidance and support.

Jane relayed concerns about the lack of clarity in the information conveyed by her husband's neurologist:

We made an appointment with the neurologist, who then tested him with this Neurotrax test. And he said to us ' "Out of a score of 100, when you get to 80, we're concerned. My husband scored 43. I was flabbergasted. I said, "Does this mean he has full blown dementia?" Never used the words; put him on Aricept. My 16 year old daughter saw the Aricept and said, "Does Daddy have dementia?"

Jane went on to describe an experience during a hospitalization. Her husband had an episode of confusion that prompted them to seek immediate medical attention. Her husband's history of alcohol abuse influenced the medical team's decision to treat his symptoms as delirium tremens related to alcohol withdrawal instead of dementia. Jane described her experience in a tone of bitter frustration:

So they put him into the psych unit and nobody saw him over the weekend and I went in on Monday and the most horrendous doctor was the head of the department and says, "Okay, I'll evaluate him now," so he went into the room and M. gives him his history and he's clean for 25 years, dah, dah, dah, dah, dah, what makes you think you have dementia? Well he was diagnosed with dementia. So he gives him a test and he says maybe it's just delirium. I said, "He hasn't drank in 25 years, it's not like yesterday." I signed him out AMA.

Jane described that her quest for information was satisfied through meetings with other dementia caregivers, not from health care professionals. She conveyed that her ease in engaging in conversations with others was an advantage because:

Nobody said to me, well this is what happens, they lose their emotions. I learned this stuff through a dementia caregivers' group not through the healthcare profession. So I'm learning things that way and luckily, I'm the type of person who talks.

Lynne explained the behavioral changes that led to her husband's diagnosis and the lack of forthright information from their health care provider:

And he (her husband) would repeat things. He would ask you a question and then repeat it and then repeat it and repeat it, like you know maybe five times. At the time I did not know that he had Alzheimer's. I mean we were just thinking it was related to the episode when he felt a "pop" in his head and no one seemed to address that, they just kind of pushed it to the side. Put him on Aricept, then not too long after that gave him Namenda and that's when I looked at the box and I said to him, "You know, does he have Alzheimer's?" And he just shook his head and he walked away, really fast and needless to say, we did not stay with that neurologist because of it.

Lynne described a barrage of doctors' appointments and the disappointment she felt in finding out that little can be done. Lynne shared:

We had gone through so many doctors' appointments and, you know, so running around everywhere, they wanted to do a spinal tap and M. at the time he said he didn't want it. He said he was tired of doctors and he really didn't want it and he said we'll take a break. The idea, he (the doctor) said of a PET scan, he wasn't thrilled with it, Dr. N., because he said it would give a false positive and then you might live the rest of your life thinking that you had something that you didn't have. He said the point would be, you know, that you'd have an answer, but there's nothing changing. You know, everything is still the same.

Doris expressed her perception that health care providers should be doing more to find out the causes of dementia. "Yeah that's what fascinates me. That's why I'm like how do you not study and research these people." She complained, "I don't get any real answers from anyone."

Lack of guidance from healthcare professionals was sometimes a factor in situations

concerning safety. This was a particular concern when it came to deciding if the person with dementia was safe to drive a car. Jane sought guidance from a neurologist but ultimately it was a lawyer who helped with making this decision. According to Jane:

When we went to the doctor, the neurologist, I said, "Can he (her husband) drive?" And he said, "Drive with him, if you feel comfortable, he can drive". Well, we went to the lawyer to put all our stuff in order. She said, "M..., you can't drive anymore. If you have an accident and you have this diagnosis, they're going to; you're going to lose everything. He handed the keys to me and that was it.

Sometimes, spouses living with a partner with younger onset dementia disclosed the perception that healthcare providers did not take their voiced concerns seriously. Jane conveyed how she felt belittled when she tried to relay her concerns to her husband's doctor:

We'd go into his (the doctor) office and I'd say that I gave M. (her husband) the phone, he (M.) went into the basement, he came up and he couldn't remember where he put it. And the doctor's response to me was, "My wife yells at me all the time because I lose the phone." Okay, well, maybe you (the doctor) have dementia then. Like it was, (pause) he was almost like poo-pooing what I said.

Lynne also relayed an experience in which a psychologist focused on her response and not her husband's behavior:

I set my husband up to see a psychologist when he got fired because I thought that he would be very devastated after 30 years of service and he (the psychologist) kept laughing at me and saying, "You need it (therapy), more than he (her husband) does". But not in a way, not in a tone that was helpful to me. More like making me feel like I was some kind of crazy lunatic, like I'm the one that had the issues.

Lynne divulged how things evolved in their meetings with the psychologist. She continued to try and explain what she was seeing and eventually the psychologist indirectly delivered a diagnosis of Alzheimer's disease by handing her a card with contact information about the Alzheimer's Association. Lynne stated:

And I kept saying to him (the psychologist), but I'm seeing this and I'm seeing that and we went for years like this until one day after questioning my husband, he looked at me and passed me a card to the Alzheimer's Association and said to me, " You need to get him on Medicaid. As a matter of fact, he should have been on it a long time ago. And I looked at him and said, "Well you kept telling me that I was the one that was out of my mind, technically. That I was making something out of nothing. I tried to tell you that this is what I'm seeing." So, I think the providers need to take the information from the spouse or children or whoever it is and really believe.

Sometimes, lack of interpersonal skills in communication served as a source of dissatisfaction for some of the participants. This may be related to the shock of hearing an unexpected diagnosis.

Patty described her perception of how the healthcare provider delivered the diagnosis of dementia. She said, *"First diagnosis I got was from Dr. ... and he was very factual. Gently but very factual and I didn't like him. He did everything right, but I didn't want to hear him."*

Rose conveyed a similar reaction when she stated, *"The first time we went to the neurologist, I didn't care for her. She was a good doctor, she diagnosed you know correctly, I think her medical degree is fine, but she has zero people skills."*

Seeking treatment for unmanageable behavior was fraught with unsatisfactory experiences. Some of the participants shared that admittance to a psychiatric setting was the only alternative, yet this setting was not prepared to deal with the special needs of a person with dementia.

Lynne described her experiences in seeking help and trying to find treatments for her husband's symptoms:

Every time he went to the hospital, the doctor said, "He's not psychotic, he doesn't need this type of care (psychiatric), he's got dementia, classic dementia, Alzheimer's dementia. The things that he's doing are not unusual; they're not out of the ordinary. There's nothing that he needs to be in a psychiatric unit for.

Woody explained her approach to enhance interactions with health care providers while seeking answers, stating:

I would send him (the healthcare provider) an e-mail. So prior to us coming to an appointment, he kind of knew what was happening. Because before he was kind of talking in front of G. (her husband) and he was getting a little upset so we worked it out that way.

Woody described several interactions with healthcare providers and shared her perceptions. She depicted a distressing encounter with an emergency department doctor when her husband was taken to an emergency room after he fell at home. When she called 911 for help in lifting him, EMS insisted on taking him to a hospital to be evaluated:

Then the doctor comes over and I don't know where they got her from and I'm trying to explain my husband has Alzheimer's and he's in the later stages. And she's says, "Well I think we need to do a CAT scan and we need to". And I said, "Let me explain it to you, he cannot tolerate a CAT scan and if you do it and find something, what are you going to do? There's nothing you can do. He does not need a CAT scan. He has Alzheimer's, he fell. Anyway, we wound up being there half the night. They didn't find anything.

Woody continued her description and how she tried to serve as an advocate for her husband. She attempted to convey to the doctor the need for sensitivity in dealing with her husband who was confused and frightened:

So the next doctor comes in, here again, he's poking him. I said, "Do you understand he has Alzheimer's. I don't know what's going on in his mind but he doesn't understand that (poking). I said, "How would you feel, close your eyes, how would you feel if somebody's poking you and I did that to him and he stopped. But it's just amazing how people don't understand and you have to try to tell them.

Doris depicted a picture of insensitivity in interactions with healthcare providers. She voiced frustration with the clinician's mechanical approach and lack of insight into how to interact with a person with dementia effectively and with concern for their dignity. Doris shared:

Any time we walked in and he'd (her husband) hop on that table. Okay we're going to do this, do that. Say three names (she claps her hands quickly three times), give me the colors, give me yellow, give me orange, it's like whoa, and slow down. They need to have much more patience, compassion, remove the clinical side of it because it really is not just the knee; you know it's not just the knee reflex. It's sort of like you're sitting there with a person that's staring at you, like he has no idea what you're talking about.

Doris continued to describe her positive and negative perceptions with healthcare providers. When the doctor suggested a spinal tap, Doris stated, *"Then it's like you tell him, let's get a spinal tap, you're talking like I'm going to get a little ear swab."* She went on to describe an experience with EEG monitoring:

These are invasive, metal, you put 60 electrodes on your head for 45 minutes and him pulling them out of his hair and there's no bedside manner." Doris described a positive experience, *"I love the speech pathologist, the therapist we had is wonderful. Anyone that does therapy for neurology, they're like exceptional."*

Minnie spoke with frustration as she described one doctor's visit. *"We went to his doctor and his doctor said, P. you never looked better. And he had lost a lot of weight and did look healthy."* Minnie concluded, *"They're (healthcare providers) not much help."*

Patty related how the knowledge that she was caring for a spouse with younger onset dementia affected her interactions with her provider regarding her own personal health care issues:

The moment they know you're a caregiver you get all this sympathy, like I'll (the health care provider) be really careful. In fact, my doctor didn't tell me I had an ulcer. I don't even know if that's allowed, but he didn't. I told him I have a terrible stomach, I've never had this before. He gave me this medicine and I looked it up and it was for stomach ulcers.

Lynne succinctly conveyed a message for healthcare providers; a ubiquitous finding in the narratives of all nine participants. She stated, *"Well, I think my top thing would be is, they (healthcare providers), need to listen to the person who's living with the person with dementia."*

Things are constantly changing

The pervasive presence of unpredictability was thread throughout all of the participant narratives. The stories portrayed a picture of confusion and frustration as the participants described dealing with an ever-changing set of behaviors in their spouses. This was described by Jane, as she talked about how her husband could seem “normal” for periods of time, followed by periods of illogical thinking. Although she expressed that this is part of the disease process, she stated, “But it always takes my breath away a little bit when he says something like so off the wall.” She shared one example when she was telling her husband about a possum in their backyard and she realized he had no concept about the type of animal she was talking about. Jane went on to explain how she learned about the prevalence of unpredictable behaviors in individuals with dementia from other dementia caregivers:

I went to a dementia support group and I was talking about it (unpredictable changes in behavior) and this one woman said, “I have to tell you, my husband’s home, he hasn’t been in program (adult daycare) for a little bit. He’s the most meek and mild man ever, and kind, absolutely sweet, kind. Well he was home, they got a home health aide and something happened. I don’t know what the guy (home health aide) was doing but her husband ended up breaking the guy’s hand and wrist.

Capabilities varied greatly and understanding how the affected spouse could perform some tasks well but demonstrate inconsistency in their abilities was perplexing.

Lynne described one example in which her husband covered up his forgetfulness:

He would take the dog out for a walk and it could be in the winter and he’d come in and he’d go right back, saying, I have to walk the dog. And I said, you just walked the dog. In the beginning, it was a little frustrating and he would try to cover certain things. After a while, I would say to him, “You know, your body is cold. Don’t you realize that you were just outside?”

There were some instances in which memory lapses had a significant impact on the family’s financial security. Lynne shared a story about her husband’s loss of income:

My husband worked a lot on commission. He got a straight salary but commission was his big money. He came home one time and it was time to pay the mortgage and I asked, "Where is your commission check and he replied, "I don't know." So I said, "You know did you lose it or did you know something else happen?" He replied, "No, no, I don't know." So I said, "Well what are we going to do?" Then he said, "I think they might have told me that I'm not getting that anymore."

Jane shared her confusion about the constant changes. When she spoke about it, she said, "I still find it very hard to understand how he can do certain things." She used a story about a friend's experience to try to make sense of her husband's fluctuations in cognitive functioning, saying:

But a friend of mine's husband got on the train, went to Manhattan, walked around Manhattan, came back and she ended up having to hire someone to follow him. So I guess that is part of the brain that just doesn't go away.

Woody described the volatility of mood changes that she encountered. She shares how things can be calm and seem normal and then quickly escalate out of control:

We were watching television, he was laughing, and it was good. I said come on G., let's just go in the room so we can go to bed. And here again, you know, I have to help him take his clothes off. Well, I helped him take his pants off and he's like he wanted them and I know I shouldn't have done it but I did it anyway. I grabbed the pants from him. And he just went (she makes a whoosh noise), I want to go home, I want to go home, where's the cab, I want to get out of here. I want to go.

As Woody continued the story she included how her daughter attempted to help but the situation resulted in a physical confrontation.

My daughter's like, Dad, I love you, what's wrong and usually if I say come on let's have a prayer, he's cool but he didn't care. So we're in the back room, I got in front of the door. My daughter was like Mom, I just knew he was going to hit you.

Sometimes, the changes in behavior were perceived as an improvement from premorbid personality. Rose shared her perspective. "The one thing about the probable Alzheimer's that he

has, is his personality in certain ways changed for the better. Before he'd be flying off and get angry quickly; he would be grumpy a lot."

Patty described dramatic changes in her husband's abilities and how it affects her daily life. She explained, *"He would always be cooking. Now, he doesn't even take his dish out of the closet. He can make cereal, where he pours milk in the bowl and there's no cereal there yet."* She went on to describe that, *"Every week I'm learning something new."* Patty talked about the challenges of planning, when she spoke about an upcoming visit with her daughter and grandchildren. *"It's in two or three weeks. My daughter's coming, but two weeks from now? Three weeks from now with her kids and staying here (in the couples' apartment). She thinks she can. I don't know. We'll have to see."* Finally, Patty described practical concerns about her husband's cognitive and functional decline. *"So things are constantly changing. What I'm thinking about now is whether he's going to choke on his food."*

Sally depicted the subtle changes in her husband's behavior in the beginning stages of his dementia. This was apparent in her husband's disconnect with time of day and alterations in sleep cycles:

He would go to work on his day off. And he'd come home and say you wouldn't believe what I did, I'm off today. But there's a schedule change so you would say, oh well, I guess that's why or he would get up really early in the morning, like one o'clock in the morning and take a shower and think it's time to go to work.

Sally described how her husband's behavior evolved into a roller coaster of mood swings that affected her entire family, as the couple still has young adult children living in their home :

He'll go like who left this s..t around? Who left this, G..D.. slob, the whole thing and then he'll really get worked up and then he goes up and slams the door and that's the end of him for the night. And then he'll wake, you can wake him like if he doesn't take his

pills. I'll say take your pills and he'll say something mean and then I wait like two or three hours and then I can give them to him.

In spite of the volatile nature of her husband's behavior, like Rose, Sally described a positive aspect to her husband's changes in behavior:

He doesn't get that rage until nighttime but like I feel like a weight has been lifted off of him. He doesn't get uptight. He was always really very uptight. Like you'd see a dog and you'd pet it and he'd say, "He could have rabies, it could be this, and it could be that." Now he feeds the squirrels. Yeah, so I feel like he's nicer.

Doris spoke about the rapid change in her husband's functional abilities. She expressed emphatically, *"It's hard to describe because all of a sudden you go from one extreme to another. You know I'm (her husband) independent, independent, independent but now he can't even open the refrigerator."* She went on to explain challenges in getting her husband to take his medication, *"A few months ago, that wasn't a problem. Today, it's maybe I'm running out of the applesauce option."*

Minnie explained how her husband's declining abilities affected his employment. She stated, *"But then subsequently within that two year time period, he would get a job, lose a job, get a job, lose a job."* Minnie continued to describe other changes in her husband's normal participation in household chores such as cooking the family meals:

My husband was a chef. So he'd cook great things and pretty much whatever you wanted. But because cooking is very process oriented, he's not able to do it, do the process or make it come out right. So most recently, he has stopped unless we force him. He has stopped cooking and he's also stopped worrying about eating, which is another story.

Minnie voiced concern about changes occurring in her husband's behavior:

I can see him getting more and more stubborn and there is something going on. I mean, I don't know what it is right now or where it's going to go, if it is going to be a new sense

of normal or not. So we are just kind of in this period right now, which is a little awkward.

She concluded by saying, *“He doesn’t remember where we’re going or why we’re there or what we did that day.”*

Doris described the impact of the uncertainty of the trajectory of her husband’s dementia when she stated, *“I’m like is that ten years from now, is it next week, is it six o’clock today? And that’s what I said to everyone every day the shoe’s dropping (she snaps her fingers rapidly).”*

Lynne described the impact of dementia on her husband’s personality. She said, *“My husband is a very sweet, easy-going guy, but this disease takes a toll and makes a different person out of people.”* She depicted a situation in which her husband became combative which was very uncharacteristic of his usual demeanor:

The problem we had since he became incontinent was he didn’t want anyone (to clean him up)—I think it’s a modesty issue for a man, he’s 61 years old now, I mean, he’s not old, he doesn’t have co-morbid issues and he would fight (getting personal hygiene).

As the participants described the maze of uncertainty, a wide range of emotions were communicated. This segues to the next theme, A Kaleidoscope of Feelings.

Theme 3: A Kaleidoscope of Feelings

According to Merriam- Webster’s Online dictionary (2017), a kaleidoscope is an instrument containing loose bits of colored material (as glass or plastic) placed between two flat plates and two plane mirrors, so that changes of position of the bits of material are reflected in an endless variety of patterns. A second definition by Merriam-Webster (2017) states that something resembling a kaleidoscope as a variegated changing pattern or scene; a succession of changing phases or actions. With this visual depiction, the following section illustrates the range

of emotions revealed by the participants in this study. Much like a kaleidoscope, the feelings occur and re-occur in no particular order and in fact can be present simultaneously. The emotions expressed throughout the participant narratives were: anger, being overwhelmed, guilt, embarrassment, frustration, fear, and hope.

Anger

Anger is defined as an intense emotional state of displeasure with someone or something (Retrieved from [www. merriam-webster.com](http://www.merriam-webster.com) 2/27/17). Expressions of anger were revealed in the words and voices of the participants in this study. Sometimes, it was expressed as a direct feeling towards the spouse with younger onset dementia. It was also directed at other people such as family, friends and healthcare providers. Lastly, the disease of dementia itself evoked this intense emotion.

Jane expressed feeling angry that she has to work, while her husband sits idly at home:

It makes me angry because I'm working hard and I think it's not healthy for him to just sit and do nothing. He cut himself down to three days at the adult day care program, when he was going five times a week at one time.

Doris revealed how her husband's behavior evoked feelings of anger and described how she controls her reactions:

Now because he yells, he's nasty and combative which in my nature alone, I would never stand for that. Just sit there and be submissive and have someone screaming at you? I'm like this isn't good. I'm like breathe and that's what I do. I'm like (takes a deep breath and sighs) because I would punch him, I would just punch him.

Jane described feeling angry when her husband chose to spend time with his friend instead of with her:

I asked him to come walk the dogs with me. He said, "No, I don't want to." But then I come home and he's gone with his friend to walk up to Shop Rite. It's very infuriating, you know? So it feels like I'm more a mother than a spouse.

In some instances, the anger was focused on the dementia. Lynne described her reaction to the situation in a general way. *"I don't know, I guess I got really angry at the whole situation."* She went on to convey feelings of anger towards her husband's healthcare providers.

I felt like maybe this (getting dementia) could have been avoided. I had anger towards the doctors because he (her husband) had just had a physical and a complete work-up, a stress test and all and how could this be possible. All of a sudden now he has Alzheimer's disease?

Rose described the complicated path she has traveled beginning with her husband's alcoholism and an evolving series of challenges.

How many times I said, I'm leaving you (her husband), how many times did I say that? Ridiculous it's such a cliché. But he did stop drinking for two years because I said your memory is really an issue here. If this is an alcoholic dementia, this can be reversed from what I read.

Rose depicted the multiple events in her life that contributed to feelings of anger:

The fact that it was all the years, like a good seven years of alcoholism, that was like disgusting, getting hit by Hurricane Sandy was not a minor issue. I was diagnosed with breast cancer, no big deal. I'm fine; it almost doesn't make the list. His cognitive impairment, and then this (episode of infidelity)? It's like but now I'm caring for this man. If it was just one thing, it would be a challenge. With everything, it's like this is ridiculous. But I told him in one of our more heated discussions, "Look, I'm a volunteer here. I don't have to be here."

For some participants, their anger was directed at family and friends. Rose spoke with empathy for her husband as she told a story of about friends making jokes about her husband's cognitive changes that they thought were related to drinking alcohol:

It's very hard to watch. I've seen him do things last year at the beach that broke my heart. When I see other people being disrespectful, I just want to kill them. You know he was a battalion chief in the fire department, he was a big deal. Everyone sucked up to him.

Doris expressed anger directed at family and friends for their lack of support in helping to keep her husband safe:

The best is, I told everybody, I'm like look out for him. If you see him walking by himself, that's not good. What does everybody do? People wave and that's great (shakes her head). I'm like did you not all hear me, you all answered me too. I'm like you all responded saying don't worry, we'll look out for him. We were here (the couple had just come from another state to New York) and within 24 hours, he's gone and he ends up going back to our old bar restaurant that we used to hang out in.

Doris poignantly described feelings of anger at how she perceives that their friends have abandoned them:

It's terrible, you all walk away. We're sitting at brunch by ourselves. And that's why I think, I 'm getting in that angry frustration stage. And that's why I think people get very taken back because as he's lost his filter, I've lost mine. I just say it like it is now, where I never used to do that. And don't say that everything happens for a reason. Can't stand it. Worst words ever created in America.

Doris voiced anger at friends and family for assuming her husband has Alzheimer's even though no definitive diagnosis was ever identified:

It's a mental illness, his early onset dementia with unknown reason. But people just don't see it. And it's that stigma, like he has Alzheimer's. No. He does, yeah, yeah, that's Alzheimer's (referring to what friends and family are telling her). I'm like okay; did you go to Alzheimer's school? Like how do you know? Do you live it? They're like no, but that's what everybody says it is. I'm like people don't know it and get it unless they're in it.

Minnie expressed anger at her brother's reaction to her husband's unemployment and lack of understanding. *"In the beginning it was a little hard. My brother's like, my sister (referring to Minnie) is always looking for a scheme. Now, her husband doesn't have to go to work. And I was really pissed."*

Overwhelmed

As the participants spoke about their daily lives, a sense of being overwhelmed and loss of control was communicated. This was complicated by the unpredictability of behavior from day-to-day and being unable to anticipate what the future will look like.

Patty described her reaction to her husband's changes. She explained, *"Every time he kicks in with something new, I lose it, a little bit."* Patty continued to share how this has affected her ability to react to other events in her life. She states, *"And I'm much too involved in E. to get upset about this."*

Rose depicted her feelings by stating:

I don't know what a good day is, and what's not." She stated, *"I equated it with, I feel like I'm trying to save a drowning man. And he keeps pulling me under. And there comes a point where I have to kick him away and save myself."*

Sally stated in a monotone voice, *"I'm done. Like my life is just done."*

Woody talked about an experience related to her husband's admittance to a psychiatric facility. It was very distressing for her and her children to see her husband medicated with anti-psychotic medications to control his behavior:

He was really drugged up and you know, he still had a little edge on him but he was really drugged up. It was a very emotional time for me, my son, his wife, and my daughter. And you know, I was just crying, I was just like it was so sad and my daughter and I had come to terms with it, with God. It was like Lord, we do not want to see him this way. Take your angel home and that's how we felt.

Jane expressed how feelings of being overwhelmed fluctuate day to day but is a constant presence. She described the burden of responsibility:

I think I go up and down in waves where I'm dealing very well with it (her husband's dementia) and then he'll do something and it kind of smacks me right down to earth. Like

how much more, you know? How much more can these shoulders hold. My husband, my children, my house, my mother-in-law; like I'm responsible for it all.

Lynne described how her husband's functional decline caused her to have a "breakdown." She described her husband's loss of bladder control as a significant contributing factor:

So we got to the point where he needed to wear adult diapers. He was coming home from the adult day care program and he was saturated, he was wet. That was about a year ago. I started to look into (placement) because I had to. Like, I don't even know what kind of breakdown you would call it but I just couldn't take it anymore and I had called the Alzheimer's Association many times without a lot of result.

As some of the participants described being overwhelmed, they conveyed messages of wanting it (dealing with dementia) to be over. Doris pronounced that, *"I'm at the point where, I'm like whatever, like I don't care. Whatever. Go. And not in a bad way—I'm just like go."* However, she stated, *"I'm like I can't take him to a nursing home. No matter how bad, I'd rather him be dead and honestly, God forgive me but I pray for it all the time."*

Patty stated with tears in her eyes, *"Things are being taken away, so he can't really communicate with me the way he did before. I almost, I, I, when and don't wish for something. Because I really wanted out of it every once and a while."* She could not bring herself to verbalize the words.

Guilt

Feelings of remorse were expressed by the participants about a variety of topics. The topics included: their inattention to the changes in their spouses, taking time to care for themselves, and how they managed dealing with a partner with dementia.

Lynne described how she wished she had paid more attention to her husband's early symptoms and implied that maybe the outcome would be different if she had been more engaged in what was happening:

I wasn't really focused on him because he wasn't ill, he was never, you know, under any medical restraints, or had any problems. But when I look back, I really know it sounds weird but I thought his skin looked very dark to me, but I thought it was because he had grown a goatee. I wasn't focusing on any illness because he wasn't sick. It's been difficult. I feel very guilty.

Similar to Lynne, Woody admitted that she "felt guilty" about not noticing changes in her husband sooner. She described an early situation in which her husband got lost driving in an area that he had been familiar with in the past:

I noticed some things and I feel real bad because I didn't pick up on it. But then I started noticing some other things and like I said, I feel bad because I just didn't pull it all together. We would go driving, some place where I knew he would know how to get to and he would get a little turned around and I was like G., you needed to go here or hey you didn't stop at that stop sign. And he was like; well you know it because you travel this way all the time and I haven't been out here in a long time.

Sunny expressed a comparable sentiment when she stated, "I mean there were probably little things that I just was not really paying attention to."

Sally spoke about feeling guilty taking time for herself. She stated, "I would just be like I'm going to the gym and slam the door. Then when I found out he was sick, I felt bad. I felt guilty about going to the gym so I stopped going." She went on to express feelings of guilt about her work schedule and its' effect on her husband. She proceeded to explain, "And I feel guilty because I'm working late now and that's when he seemed to get worse. I don't think I'm really doing anything right."

Minnie described her feelings in a pragmatic manner as she explained her focus on her own needs:

I'm sure I handled it all wrong, but you know, I think the first thing you need to do is kind of get yourself in order and you know, figure things out for yourself. Where you're going to be, what you're going to do, how you're going to support yourself.

Jane stated, *"I have the dogs and I have my sisters, so I get out when I can but sometimes I feel guilty getting out."* Jane reminisced about the couple's early relationship:

Should we have had a date night more often? Sometimes you get that guilt, I shouldn't feel this way. He let you be a stay-at-home mom for so many years. You have done what you really wanted to do and now you need to take care of him and it's just like okay. But I don't want to have to wipe his butt and I don't want to have to put him in the shower.

Patty explained her conflicted feelings related to being torn between spending time with her grandchildren and taking care of her husband. She stated:

I don't feel like waiting until he dies to be able to see them in their activities, it's a terrible thing to say. I don't get annoyed at myself for not doing things, I guess. I do forgive myself, well maybe not.

Frustration

The medical definition of frustration according to Merriam-Webster (2017) is a deep chronic sense or state of insecurity and dissatisfaction arising from unresolved problems or unfulfilled needs (Retrieved from [www. merriam-webster.com](http://www.merriam-webster.com) 2/27/17). Although frustration and anger are terms that are often used interchangeably, the preceding definition captures the applicability of this subtheme in depicting the concept of frustration as expressed by the participants in this study.

Jane expressed frustration that her children didn't really understand their father's behavior, when she said, *"I hate to keep saying, it is part of the disease, it is part of the disease. Like I wish my kids would sit down and research it a little bit."*

In a similar message, Rose described her reaction to her husband's family and their lack of understanding about her husband's dementia:

But his sister and his brothers were in denial a lot about this. And it was very hard for me. Very, very, upsetting to be cast, once again in my mind as the villain. I was the villain with alcohol. I'm now the villain with this other thing. And you know, you shoot the person who gives the bad news and I'm tired of giving bad news. Told everyone, I'm sick of being the Debbie Downer who has to tell everybody this stuff.

Sunny described how her husband's inability to complete seemingly simple household tasks evoked strong feelings and how she reacted.

He always cleaned up the kitchen. But now he doesn't. You know, something still has soap in it or he'll forget that the dishwasher's clean and he'll put the dirty dishes into the clean dishwasher. So if I'm tired and in a bad mood, and I'm like oh God, and if I get like all (worked up), I can't believe this. I'm not even yelling at him, I'm just yelling in general.

Sally described a similar reaction to her husband's daily routine.

He keeps himself busy but he doesn't do anything. He tells me he cleans the whole house but nothing is done. Or I'll send him downstairs for a roll of paper towels and he'll come up like 20 minutes later without it, like he forgets what he's doing. He washes dishes all day long, though. And he doesn't have to, we have a dishwasher.

Minnie spent a large portion of the interview time verbalizing a wide range of frustrating situations. She described her reaction to her husband's daily routine and inattention to household chores.

I don't know what he does to be honest with you. But like he doesn't initiate anything. So I mean, he'll see a broken handle- door knob for like a week or two and I'll think like, are you going to fix that?

Minnie went on to explain feeling exasperated with her husband's lack of problem-solving skills, things that she perceived he should be able to handle without her help.

So that's the problem is he doesn't know like if his battery dies, I have to charge it, he can't solve problems. So that is, you know, or call me because your cell phone ran out. Plug's right there. You have got like a battery pack, just press that button. So that kind of gets me a little –frustrating.

Minnie described the impact of her husband's lack of communication as that had been an important part of their relationship prior to the onset of dementia.

And I would get extremely frustrated because I didn't know what he was, you know, what he was feeling because he wouldn't talk about it or what was happening. He'll never text me, he'll never call me like hey, and I didn't see you or where are you again? Or check in with me. I think that's kind of like the most frustrating part.

Minnie voiced feeling irritated that her husband was able to remember one activity that he always remembered to do, in spite of lapses in almost all other areas. She shared that “*There's one activity that he does do. He's a rules official for a golf association and he loves golf. So, he has his own calendar and he never (stated emphatically), forgets to go to that.*”

Patty explained how she felt about her husband constantly losing or misplacing things especially money.

He does not have a checkbook anymore. He does not have a wallet. Because he kept losing both of them and I couldn't stand it. So after a while, I just said, you have what you need and if he says he needs money, I just give him a ten or a twenty.

Woody expressed her sentiments about how caregiving responsibilities limited her ability to leave the house. She stated, “*And sometimes, I felt like a prisoner because I couldn't take him out.*”

Jane voiced her reaction to participation in a dementia support group and her relief to find someone in the group who validated her feelings.

When I went to the dementia group, everybody's got these wonderful happy families. And they're in love with their husbands. Thank God, there was one woman whose husband was an alcoholic and I mean, I feel bad for her too, but she would just say, f— him, I don't care, why doesn't he just die? And I was like, I feel like that sometimes too.

Like it's I put up with this for so many years. I took care of finances since the day we were married because he was a gambler.

Rose described a poignant scenario in which she was frustrated and angry with how “friends” treated her husband when they met them while walking at the beach:

He (her husband) had a t-shirt, like we have on and went to put it on. It's like three of the guys on the beach were all knocking back beers and stuff and they all became shocked—and I didn't know what to do. First, he put his head through the arm (of the t-shirt). Then he took it off and tried it again, all the while talking and he couldn't get his shirt on. And one of them said, “How's that sobriety going for you?” I wanted to kill him because I wanted to go over and help him but I didn't want to treat him like a child.

Embarrassment

Several of the participants described situations that caused them to feel embarrassed about their husband's inappropriate behavior in front of other people such as disrobing, agitation, unpleasant eating habits and inattention to personal hygiene.

Patty described how her husband's eating habits diminished her interest in going out to eat; a past-time the couple had previously enjoyed doing together. She explained why:

Honestly, when we were sitting together, I almost can't eat with him because he sounds like a cow. It is just awful. In the beginning, I used to say something to him but then I realized, stop it, it's not helping.

Patty expressed embarrassment in her husband's behavior on an airplane. She explained:

“Coming back from California, he was putting his seatbelt on, taking it off, and putting the table up and down. Not screaming but driving everybody nuts.”

Woody spoke about her husband's multiple falls and her embarrassment that emergency personnel had to come and find her husband partially clothed. She stated, “*Now this is one of many falls. And every time he fell, I'm like why do you fall half naked? Anyway, he just had his underpants and undershirt on.*” Woody described another scenario which focused on her

concern for her husband's dignity. In addition to having dementia, her husband is morbidly obese, weighing over 400 pounds. She depicted an episode in for which her husband fell and she had to call for help from the local fire department:

Usually I'm on the right side of him (helping her husband in the bathroom) but for that day I decided to get on the left. So now, I'm pinned by the window and him. And I'm like okay; I got to figure out how I can get out of here. I'm trying to call my daughter but she couldn't hear me because her door was closed. So I got his pants off one leg and I was able to climb over and I had to call 911. The EMT people came and they're like we need help. They call the fire department; it must have been six of them that came. How are we going to get him up? I was so hurt and so upset, how his dignity, it was gone.

Patty described her embarrassment at her husband's disrobing at inappropriate times and how that has restricted their social activities. She said, *"Because what if he does take his clothes off. He does that a lot lately. And he might do something really inappropriate."*

Sally expressed awkwardness when she sees her husband's behavior with other people and their reaction to him. She said, *"He walks the dog a lot and he talks to anybody he passes. He walks the dog over to them and I think he annoys people a little bit. Like oh here we go."*

Doris expressed concerns about her husband's lack of interest in personal hygiene and how others may react to him. She explained,

Now he sleeps in his sneakers and the same clothes. I mean I had to brush his teeth yesterday. If I don't shave him, he won't be shaved. Especially because he's from this town (where people know him), if he goes out (what will people think)?

Fear

Fear was expressed related to several issues. One of the major concerns was the fear that the individual with younger onset dementia was at risk for harming himself and/or others. Several participants voiced fears about their own health and well-being and/or that their children

may be stricken with dementia. Fear of the future, the unknown course of the disease, and how they would manage their daily lives was woven throughout the narratives.

Doris relayed concerns about the safety of her husband continuing to drive. She described her reluctance to stop her husband from driving even though she believed it was unsafe.

I'm like; if you want to crash into a pole, go ahead. But I'm worried about someone else that he's going to harm. So I call the police and then they don't do the lights and sirens, they just pull him over. They're like what do you mean he stole the car? I never turned him in, I never turned his license off, and I never reported it.

Jane voiced her fears about her husband's inevitable decline and how that will affect her life and her ability to keep her husband at home.

My big concern is what's going to happen to me? Where am I going to go? I wouldn't put him in a nursing home until he had to be put in a nursing home. Until it got way too much for me. I would do community Medicaid and have somebody come into the house for him. But that's still a ways away.

Jane expressed her concerns about what would happen to her family if she was afflicted with an illness and how that would affect her ability to care for her husband.

What happens if something happens to me and that's a very realistic, scary, scary thing. My brain always jumps to the worst. So whenever I get that little hiccup, I devastate about the hiccup and devastate about what happens to everything else because once the bottom of the deck of cards gets knocked over, the whole thing comes crumbling down. And that is to me a real, real thing.

Several participants voiced concerns that the disease would be passed on to their children.

Jane said, *"I worry about my kids getting it. I'd like to see research done and I will donate my husband's brain when it comes down to it."*

Sally also voiced concerns about her children. She said, *"I'm worried if my kids have it. That's my biggest fear. That they're going to catch that (dementia). That they'll get it, especially the younger one because she played soccer. Took a lot of balls to the head."*

Rose spoke about how her husband's increasing dependence on her to take him places limits her freedom. She said, *"All the doctor's appointments, I take him to because he can't remember where they are. That's new information. Around town, he can go to his Alcoholics Anonymous meetings. I dread when that stops."*

Anticipating upcoming events was difficult for some of the study participants. Woody verbalized her fear about how her husband would act at their son's wedding. She stated, *"Last year our son was getting married and I was really nervous about how that was going to be."*

Rose spoke about the lack of privacy that would occur when it became necessary to have help in their home to care for her husband. She said, *"I don't want to think too far ahead but the thought of having somebody in our house taking care of him and all, it scares me to death."*

Sunny described her fear of the future. She stated, *"I'm sure for me there's a lot of denial in there. Because I'm not going to that place at the end. I'm just not going there because I'm well aware of what could be in store."* Sunny has been exposed to individuals with dementia in her role as a healthcare professional and is knowledgeable about the impending consequences of cognitive and functional decline.

Patty voiced that her anticipation of the future may be affecting her ability to live in the present. She explained, *"I kept thinking that everything we did was going to be really hard because like how was I going to get him to stop driving."* Patty continued, *"What happened in a way was that I anticipate things too much. So you can't enjoy that he's still doing things because you're thinking about like when he's (incontinent), I'm already thinking adult diapers."*

Doris voiced fears about her own health and well-being. As she talked about her situation she said, *"What am I supposed to do? Worry about where I'm going to go? I'm going to have a*

heart attack. I don't want to die. Imagine that's the stress that this stuff (dealing with a partner with dementia) causes."

Sally spoke about her fears of loss of income when her husband will require more of her time to care for him. She said, *"I don't know how long I can work. How much longer. I don't know when the kids are going to leave. Because that's a help having them here."*

Minnie voiced fears about the unknown which prompts her to continue her search for answers about what the future holds.

I'm just trying to figure out our place at this moment in time and what's going to happen next or what other people have experienced. You don't even know what's going to happen tomorrow. If it's going to happen, you know, ten years from now. I think it will just be devastating, I mean and whatever confidence he has in his ability to be active, it's just going to change dramatically. Let's hope it doesn't happen for a long time. What do you see?

Hope

Although hope was a less dominant feeling expressed in the narratives, each of the participants expressed the hope that the results of this study may help other spouses dealing with a partner with younger onset dementia. Several of the participants verbalized hope for a cure in the future and the need for research and clinical trials. One participant expressed that getting involved may help efforts to find a cure.

Patty spoke about participation in multiple clinical trials. She described one trial in particular that initially seemed to be making a difference.

A nurse came every week to administer the drug and she'd be here for three or four hours. It was miraculous at first. It was really honestly amazing. He was like back to himself; it was shocking. And I was ready to call a newspaper and say, "Hey, we found it". Then all of a sudden it stopped happening. And they withdrew the study.

Doris expressed hope that research will find a cure and emphasized the importance of clinical trials. She said, *“This isn’t going to fix your kids’ kids’ kids, if you don’t do it.”*

Jane was less optimistic when she stated revealed, *“I don’t know if there will ever be a cure.”*

Lynne expressed hope that her husband’s symptoms would be reversed and things would return to normal. *“I think I thought we still might have a chance that things were going to get straightened out.”*

Doris conveyed the hope that getting involved and sharing knowledge would make a difference. She exposed her sense of curiosity and the compelling responsibility to share what she has learned from this experience.

I just can’t have all this information and knowledge and everything and not do something with it. It fascinates me. How do you not get it? You know, drop people off (in a nursing home) and never go visit them. I don’t know how, I just can’t. It will be my mission, this is why I was, that it was divine intervention when you (this researcher) called me. I’m like God, finally, I think it’s great, I do. But I’m not expecting to change the world. But if I can help one person, then I’ll do that.

Minnie beseeched at the end of the interview, *“Do you see any good work being done any place, a neurology department, a support group, just any recommendations?”*

Theme 4: Shattered Dreams/Expectations

In each of the interviews, the study participants described how living with a partner with younger onset dementia changed their lives and altered expectations of what the future would hold. Dreams and expectations convey similar but distinct meanings. For the purpose of this study dreams will be defined as a strongly desired goal or purpose; to think about something that you wish would happen or something that you want to do or be (Retrieved from [www. merriam-webster.com](http://www.merriam-webster.com) 2/27/17). Dreams are often seen as an escape from reality and idealistic.

Expectations may also be something to anticipate or look forward to but are things or situations that one may consider probable or certain (Retrieved from [www. merriam-webster.com](http://www.merriam-webster.com) 2/27/17).

Role Change

Each of the participants described changes in their roles as a partner, alterations in the division of household and financial responsibilities, and feeling like a parent with the contemporaneous increase in their spouse's dependence on them.

Jane described how her life as a stay-at-home mom was abruptly changed.

But here I am an at-home mom, babysitting other kids. All of a sudden, we're going to have no health insurance. So at the end of the summer, I told everybody, I couldn't do it anymore. I had to find a full-time job, which took me forever to find.

Similar to Jane's story, Sunny's role as a stay-at-home mom was altered dramatically when her husband developed symptoms of dementia that ended his career as an attorney. She explained, "*He was the big bread winner. He was the one that brought home the major income to the house. I hadn't worked for many years.*" Sunny described having to take on the responsibility of driving which used to be primarily her husband's role.

You know we still go out a lot and we visit my family upstate. We travel and the biggest difference with that is he always drove everywhere and he had a great sense of direction. So that's changed. So I do all the driving. I have to make sure I have my Waze, MapQuest, you know. I have to have everything because I have no sense of direction.

Lynne also described having to take over driving, a task she was not eager to tackle.

"I only started to drive more now that I had no choice in the matter and I don't even go on the highway." This role change limited their travel plans and as a result they frequently stayed at home.

A common theme described by all the participants was feeling more like a parent than a spouse. This affected multiple aspects of the couples' lives.

As Lynne described her husband's decline she stated, *"I'll start by saying for the last probably two years, I'd say, I felt like he's more my child than my husband."*

Minnie conveyed her feelings when she stated, *"So now I feel like I have a five year old clinging to my leg every time we go somewhere. But for me it's like, me needing some personal space."*

Jane echoed a similar perception. *"I see him being, my husband being very childlike. He giggles at stuff that my younger daughter giggles at, like not in a fatherly way more as in a kid way."*

Doris conveyed a similar feeling when she stated, *"They're like five year olds. It's not a relationship. You're just a caregiver."*

Although, feeling like the parent was a common theme for all the participants, there was one story in which the spouse with dementia interacted with his wife as if she was his mother. Lynne shared this particularly interesting story:

When he first started at the adult day care program, he met a young girl. He would come home and he would tell me about this girl he had met. She obviously had deficits but she was on the young side. I would say she was like 30's, 40's, something like that. I don't remember her name now. He would say he was so excited that he met somebody and you know, do you think she'll like me tomorrow? Do you think, you know, what should I do? I hope I don't do the wrong things. He would talk to me like I was his mother.

Some of the participants described the role of parent in a manner that was protective and caring. Woody conveyed how she felt when she took her husband to an adult day care program. She stated, *"It was like dropping your kid off on the first day of kindergarten."*

Sunny conveyed a sense of empathy for her husband's increasing dependence and need for what she referred to as parental supervision:

So that was always my concern is what is he doing? His sister isn't working right now so she comes out about once a week. His parents live locally. That's been a big issue for him like my parents need to come and keep me company? My parents are going to have to drive me somewhere? That's been a hard thing for him to adjust to.

Woody explained how she filled her time while her husband was at the adult day care program. She spoke about activities she used to share with her husband that she was now learning to do on her own and feeling more comfortable about it.

This was my time and I didn't have to bother anyone else. I learned how to go to the movies by myself. How to go and have lunch by myself. Do what I needed to do. But your life does change.

Sally described the need to take over finances as she shared the following anecdote:

Our phones got turned off, our cell phones. He didn't pay the bill and he would always just handle it. I never paid a bill in my life. And then the cell phones got turned off, so I paid that on the phone. And then I took over the bills.

Patty described a unique story about her feelings of loss related to her role as a mother with her children. She explained how her children tried to protect her from having to deal with any unpleasant family occurrences and her feelings of exclusion from their lives.

My children used to tell me everything and in the last four years, I don't hear their problems or have those big discussions. I don't hear, rarely do I hear that someone(one of her grandchildren) didn't do so well in school or someone didn't get --, I hear only good things about them. So I kind of feel lost. I want to hear the bad as well as the good. And I mean I don't worry about them but like they know I can't help them and I was always a hands-on mom, a hands-on grandmother.

Minnie explained how her husband's role in the family evolved over time.

During the great recession, his job got eliminated. It was great timing for us because our kids were at a point where it was great to have him home for the first time without having

to have caregivers for the kids. So that was a great novelty. He bought his own business and had that for two years and within that time period; he started to exhibit inconsistencies in his behavior. And so, we sold the business two years in and he interviewed successfully for a job and took it but things started to snowball. I don't remember what job it was exactly but it was in the same profession and he got let go, which was like a real shock. He stopped working immediately after the diagnosis and applied for disability. He just took on other responsibilities around the house that we normally would have to pay for anyway and was just more active in the home.

Loss of Couplehood

Loss of sharing activities as a couple was depicted by most of the participants. The following excerpts integrate several previously mentioned sub-themes such as feelings of embarrassment and that the participant felt more like a parent than a partner because of their spouse's childlike behavior. These elements contributed to the overall loss of being part of couple and the loss of identity of couplehood.

Lynne described her perspective about living together in a very different type of relationship.

So the relationship was pretty much, I kind of think of it almost like roommates in that, I was a caregiver. We weren't really like a couple. I didn't feel that we could go out with people and socialize at that point in time on the same level as other people. Like we could do it but again he would do things that were very childish and so it was making it embarrassing a little bit.

Lynne continued as she explained further changes in their life as a couple including isolation from family and friends.

The last three years, we have had very little interaction with a lot of other people. Either because we couldn't get to places or because I just couldn't bring myself to sit amongst people and have people ask questions and constantly asking me, what's going on? And how is he? Everything just centered on Alzheimer's. And I feel like, although we were doing (activities with other people) and we were busy, he was kind of like in a pod.

Woody explained how her husband's behavior altered their participation in church activities. Prior to being diagnosed with Alzheimer's disease, the couple attended services together every Sunday and brought communion to members of their congregation who were house-bound. She stated, *"I would take him with me to church and it got to the point where I had to tell him that he cannot serve communion."* She provided another example in describing alterations in their travel plans as a couple. I've never been on a cruise before because when we were supposed to go on a cruise, that's when he got sick and had to leave his job. So, my daughter, my son and his wife, my girlfriend and her family and friends; we are all going on a cruise in August.

Patty depicted the couple's active social activities before her husband's cognitive changes. Her husband had been a devout member of their synagogue. She describes how things transformed. *"I tried taking him to synagogue. We would go and the regular songs that we sing every week that he should have known, he's not singing. So I decided I don't care anymore, I'm not pushing this game."*

Patty continued to describe how their life as a couple had been affected. She said, *"I'm still meeting with friends for lunch. Usually, he would have been with me. In fact, yesterday somebody said why don't we go on a cruise together and I thought, I don't think I'd want that."* Patty continued, *"As a caregiver, it's very hard because all the things that you've built into your marriage are slowly being taken away from you. I may need tissues (she started to cry)."*

Sunny concurred with the previous participants as she explained, *"So you know, just even being able to do certain things together. We used to sit and watch a movie together, he can't. A lot of movies, he can't sit and watch because he cannot follow the whole story."*

Doris echoed the loss of social activities but reported that going to the movies was one activity that the couple could still do together. She stated, *“We don’t go out a lot anymore. Mostly movies. He loves movies.”*

Sally anticipated a change in the couple’s participation in a sport they both enjoyed. She said, *“We bowled, which we still do. But it’s going to have to stop soon I think.”*

Jane described how she viewed the loss of couplehood when she talked about a project her husband did at his adult day care program.

They did an art project in which they were supposed to write on leaves what’s important to you. Well, the first leaf is hiking and nature. The next one is my daughter and I don’t know, I think our dog. And then finally on the last leaf is my son, me and camping. I was like, wow, is that how you put your priorities?

Loss of Partner

Dialogue that described the loss of their spouse as a partner emerged as a distinct sub-theme under the loss of couplehood. Several of the participants depicted the loss related to the affected spouse’s lack of empathy, not being concerned about their safety and well-being. The loss of not having an intimate partner to share thoughts and feelings with, even to just discuss the events of the day was communicated by many of the participants. Another dominant theme was the loss of a partner they could depend on for help with household chores, decisions and moral support. One of the most distressing issues was acknowledging that although their partners were still physically present, they were psychologically and emotionally absent.

Doris described this poignantly, *“I’m laughing because there is no empathy. He could care less. I might as well be an oak tree. He could care less about me.”*

Jane expressed her perspective. *“Not having someone to care for (about) me is a major concern. Because he can’t do it. Will my kids care? Yes, but it’s not the same as a spouse.”*

Lynne verbalized her feelings about the loss of her husband as a partner when she relayed a story about how her husband recognized her, but he did not know that she was his wife.

My husband is a very sweet, easy going guy but this disease takes a toll and makes a different person out of people. If you asked him who is your wife. He would reply, "I don't have a wife, I'm not married." So I think he thought of me as like his mother rather than like a wife or lover or partner.

Woody had described a very loving and close relationship with her husband. She expressed her feelings of loss.

It was very hard, because he was the guy that took care of me and was always behind me 100%. Now this person is slipping away. I never in my wildest dreams thought I would be taking my husband to an adult day care program. To watch him go in there with the rest of the people (mostly older), was very hard. It is heartbreaking to watch somebody that you love so much just deteriorate, that person you used to laugh and talk with and who was very intelligent, now can't even hold a good conversation.

Woody differentiated between caregiving for parents and caregiving for a spouse. She had experience caregiving for her parents. She movingly described how caring for a spouse is very different.

It's a lot different when it's your husband. When it's your parents, you still have your husband to give you support and give you that hug. But when it's your spouse, you've lost that person as they call it, ambiguous loss. The person is gone but the body is still there. It's not like they actually die and you can mourn and people mourn with you. The person you knew is not there, they're going. As they go away the Alzheimer's comes in and they may say and do things and it's not them. It's the Alzheimer's.

Rose conveyed the changes in her husband as a partner with an optimistic outlook when she stated, *"I still have a little piece of him. He's not much of a communicator, we can't have real conversations but he still comes out with a good, funny line here and there."*

Sunny talked about the practical aspects of the loss of her husband as a partner. She talked about the lack of having a partner who can help with the little things that we often take for granted.

I mean, thank God, I was the one that did a lot of the stuff anyways, so it wasn't too terrible to take on all the responsibilities but it is hard to be responsible for everything in the household. I think that is one of the biggest differences. If I need something from the grocery store and I'm in the middle of cooking, I can't ask him to run out and get it. Or if I need him to go take the laundry out of the dryer and put a load of wash in, he couldn't do either of those things. So those are the biggest differences. I can't rely on him for certain things that I used to. Just realizing it's all on you.

Patty described the loss of a partner with an analogy. *"It feels good to have him close but it's not the same. Remember when you're married and if your husband was just in the room with you, you were comfortable? That feeling isn't there anymore."*

Minnie expressed her loss of a partner as she talked with mixed emotions about her husband's response to her. She described this loss as distressing, feeling like her husband just doesn't care about her.

I can work for a long period of time or I can be gone (traveling for work). I mean I know he loves me and I know he cares about my well-being. We were always very independent but it seem like he doesn't ever give a s...t where I am or where I've been or if I'm home or not. I don't even know sometimes if he knows if I'm gone for two or three days.

Loss of Financial Security

All of the participants depicted how their financial security had been jeopardized by their spouse's loss of employment at an unexpectedly young age. Although only three participants reported serious financial concerns, all of the participants imparted that the unexpected and abrupt cessation of their husbands' employment had a significant impact on their lives.

Patty described that difficulty handling finances was an early signal that something was wrong with her husband. He had his own business and she noticed that *“he was paying checks twice”*. She described his reaction when she started to get involved with managing their finances after she discovered they were missing \$10,000 dollars. She stated, *“It was very hard to get him to allow me to do that”*. This was a significant shift in their roles. This tipping point prompted Patty to think about future changes. *“So when I changed to handling the finances; that was a long time ago. And I kept thinking that everything we did was going to be really hard.”* Even though Patty described the couple’s financial status as secure, she voiced concerns about money. She questioned, *“How are you going to afford this (going out to eat)? Should we still be eating out? I don’t like to take him to very expensive restaurants anymore because we’re running down on money a little bit.”*

Jane bluntly stated, *“Because most of the people when this hits you are not financially prepared. It just is one of those, you get in the hole and it’s very hard to dig out of that hole.”* Her husband was given the choice to take a leave of absence in lieu of getting fired. He went out on disability and was able to save his pension.

Lynne described how her husband’s loss of employment affected their lives. She stated, *“I was working two jobs; we were trying to keep the house which we were unable to do. Financially it took a tremendous toll on everything.”*

Sunny explained how her husband’s career as an attorney ended abruptly and the effect on the family finances. She described her reactions when she was encouraged to put their family home up for sale.

The week his secretary went on vacation, because she is very protective of him, his partners came into his office and said, “Tomorrow’s your last day.” I remember being

on the phone with them and telling them they had no right to do that. It was just a big mess. We met with our financial advisor and he said, you know, you can always sell your house. I'm like sell my house? I don't want to sell my house. Yes, we can do that at some point but I'm not ready to do that right this second.

Sally described how her husband's abrupt unemployment influenced her work schedule. She conveyed her concern that although she provides the primary financial support for her family, she may not be able to continue working as her husband's care needs intensify.

He retired because of this (younger onset dementia). So now I work until 7pm or quarter to eight before I even get out. But it's the bulk of the money so that's why I do it. I'm trying to make all I can before I have to quit (to take care of her husband).

Minnie explained how important getting a diagnosis was to ensure the family's financial stability. She said, *"I was really big on getting a diagnosis as quickly as possible because I knew we needed the disability. I felt that once we got the disability it would put my husband at ease, which it did."*

Changes in Intimacy

The participants were each asked to share what they were comfortable sharing about changes in intimacy in the marital relationship. The majority described the decreasing presence, often absence of physical intimacy. There was variation in how each felt with this change. Many stated that feeling more like a parent than a spouse affected their own interest in sexual intimacy. Several of the participants described the impact of the loss of communication and shared meaning within a previously intimate relationship.

In the interview with Patty she began to describe the change in the couple's sexual intimacy without prompting. *"I mean it's for the last couple of years, it felt to me like he would try, but it felt like having sex with a child and I was not interested"*.

She elaborated by explaining her husband's intolerance of being touched.

So I don't even attempt it anymore. I don't think he gets an erection. He doesn't wake up with an erection anymore. He doesn't let me touch him anymore. He lets me kiss him goodnight. I put him to bed the way I put a child to bed.

Patty went on to share how her husband's behavior affects her feelings about being together.

"I've never felt that way before, like I didn't want to be alone with him because we had nothing to say. It's just never happened."

Jane described a similar sentiment when she stated, *"There's no intimacy in my relationship. I don't like to just have sex. I want romance. I want talking. We don't talk so my libido is just, I don't care."* This also depicted the loss of her husband as an intimate partner.

Sally talked about intimacy succinctly. *"Now it's barely there. But that's kind of me, it doesn't bother me at all (she laughed)."*

Rose expressed a slightly different perspective. Although she and her husband are still sexually active, she conveyed a begrudging tolerance.

And so I basically let him (have sexual intercourse). I'd say twice a week, max, and I think of it almost like a care taking thing. Isn't it awful? And sometimes, it's like, it's so non-sexy for me because in so many ways he's like a child.

Rose illustrated how her husband's behavior made her feel uncomfortable, decreasing pleasure derived from their encounters of sexual intimacy. She described her husband's obsession with watching her dress and undress.

I'm not shy, you're a professional and it (intimacy) is an issue. I do talk to my therapist about it. About four years ago, he started something which I would call creepy behavior.

Almost every day he's up in that bedroom waiting for me to come out of the bathroom to see the show. Believe me, I'm not doing any fanfare here at all. He really killed it with me. I was so turned off to him and he's a big good-looking guy.

Lynne stated, *"It was more that I was taking care of him as opposed to anything else like love."* Lynne proceeded to describe the change in the couple's relationship focusing on his childlike behavior.

The relationship? There was no intimacy. Sometimes I say if this hadn't happened, I don't know. My husband is a fantastic man, he was a good provider, sweet as pie. You know, I don't know anybody who has even said I don't like that guy. I mean truthfully, no one has ever said that in thirty years that I know this man. It really became like a Benjamin Button type of thing. As years went on it became more that he was the child.

Woody lamented as she explained the changes in intimacy in the couple's relationship. She also depicted the change in intimacy as related to the transition in the couple's relationship.

You know a lot of times, one of the things, intimacy, you miss that. You miss it because it's not there anymore. You're no longer a wife. You're a caregiver and that's pretty much the role that I am now." She continued, *"You miss that intimacy, that touch, that love that is not there anymore. It's kind of gradual because the more you're doing for that person, you don't see them in the same light anymore.*

When Doris was asked about intimacy she responded with acquiescence, vividly describing how this has affected her. She verbalized the loss of her partner in multiple aspects in their lives.

I take care of a living corpse. He's gone. I just go through the motions and that's it. There's no relationship. I mean there's no intimacy of any kind. I used to be fun, joyous, and happy. You know we used to do everything together.

Minnie responded to the prompt about intimacy in a matter of fact manner. Although she described the lack of sexual intimacy, expressions of physical intimacy, such as touching and kissing were still present and mutually gratifying.

We don't have intimacy in the sense of intimacy (sexual), but we are very affectionate towards one another. I don't know if he misses anything. I don't know that I necessarily miss anything. I mean, I have outlets in other ways.

Sunny was the only participant to speak more positively about the couple's physical intimacy. She described the couple's current relationship, acknowledging that things are different but still pleasurable for both of them.

We are still sexually active. It's definitely different. I will tell you, I don't know if it's the medication and I don't like to push him too much. I'm going through my changes, so it's not as big a thing for me either anymore because we have a lot of cuddling. It's good. It's still fine, although, I think he forgets sometimes.

Loss of Anticipated Future

Several of the participants spoke about how dealing with dementia has affected their views of the future. This was illustrated by stories which described the inability to make plans, uncertainty about how things will evolve, stolen dreams about growing old together, and an overarching aura of disillusionment with their visions of their anticipated future life as a married couple.

Patty described her feelings in a soft whisper as she said, "*I was looking forward to this time of life. I was looking forward to being together. But now?*"

Minnie expressed her uncertainty about what lies ahead. She conveyed concern for both herself, her husband, and their family's future.

It's too soon to really tell what it is (the future). And how bad it is or what is going to happen next, what the next stage is going to be. So it gets frustrating sometimes, not what I expected. What will my life be like? What will his life be like?"

Despite concerns about the future, Doris expressed her commitment to her husband. She explained, *“The running joke is I feel like I’m sitting Shiva. But I’m not going to leave him. I would never do that. Because I love him, and he would do it for me.”*

Woody spoke about what she had hoped for the couple’s future. She stated, *“I thought we were going to grow old together. We were going to be that little old couple, driving the car or whatever but now....?”*

Sunny verbalized sadly about her son’s comments about his lost expectations of sharing his work life with his father. He was going to be a lawyer and was anticipating the camaraderie of being in the same profession as his father.

My older son was home with us for a year after he graduated from law school. He even said to me once, “I always thought once I started working that I’d have much more of a relationship with Dad. Or we could be together on certain things.” That is just not happening now.

Lynne speculated about what the couple’s future might have looked like if her husband had not been afflicted with younger onset dementia. She questioned if they would have remained in their marriage.

I guess what I was trying to say is, he’s a good man but because of this disease, we don’t know where we would have been. We might not have been together. Nobody ever knows. He could be a good man, I could be a good woman but maybe we wouldn’t be good together. We’ll never really know that now.

Doris described eroded hopes of the couple’s plans for the future. However she portrayed a positive perspective. She said, *“I do believe caregiving is a gift. I do believe that, but I don’t think it’s for everyone.”*

Theme 5: A Solitary Journey

The participants in this study described feelings of isolation and aloneness as they spoke about their experiences living with a partner with younger onset dementia. A major factor that contributed to this feeling was the lack of understanding and acceptance of the diagnosis of younger onset dementia by the participants themselves as well as family, friends and even health care providers.

The Stigma of Younger Onset Dementia

The unexpected diagnosis of dementia at a younger stage of life prompted an array of reactions described by the participants. Several of the women in this study expressed their reluctance to disclose the diagnosis to others, especially because dementia was thought of as being associated with “old” people. Another perspective expressed was the feeling that dementia was worse than other diseases, such as cancer, since there is no cure or effective treatment available. There was an overall sense of despondency associated with the disease itself.

Woody described her thoughts about dementia, her feelings that others do not understand about the disease, and her embarrassment explaining the disease to others.

It's just so humiliating because people do not really understand about early (younger) onset. When you tell them he has Alzheimer's, the first thing they say is he is too young. He can't have it. Yes, he can. There are people as young as 30, 45 who have it. I remember when they first starting talking about Alzheimer's. It was the old people's disease. The only way they knew anything about it was after the autopsy and you didn't hear too much about it.

Sally described the surprising reaction of her mother-in-law when she told her about her husband's diagnosis of Alzheimer's. She said, “*When I told his mother that he had Alzheimer's she was like, oh thank God, I was afraid it was a brain tumor. I'm like why is that better?*”

Patty shared her perception about the expectation that dementia is associated with aging and the same behavior in older adults is more acceptable. She explained, *“It is okay when you’re older to do the things that he’s doing but not at 73.”* Because of this she said, *“I didn’t let people know either (about the diagnosis of younger onset dementia). I didn’t want them to treat him differently.”*

Doris compared Alzheimer’s to mental illness and the barriers encountered.

Obviously, if he had a physical ailment, people understand more. But when you don’t see it, it is worse. That’s the stigma of mental illness. I always say, you’d be way better off, having a Chemo drip. I’d have 60 people on the cell saying, I’ll help you. Sixty people to come look at the ocean with him, they said they would. I’m like I saw you drive by looking the other way. I’m not stupid. You know the people that can deal with it and the people who can’t. Dementia is such a bad word in the sense that people just associate it with elderly and nursing home.

Doris continued passionately as she stated, *“It’s like addiction, it’s like cystic fibrosis, it’s like anything else you know? And that’s what I said to people, if he was sucking out of a straw with one arm, maybe I’d have more support.”*

Jane expressed her thoughts about health care providers. She stated, *“But I really would like doctors to see it (younger onset dementia) and understand that it’s prevalent. I mean if you’re not 80 years old, they’re not thinking dementia.”*

Lynne described her personal lack of exposure to younger onset dementia. She said, *“I didn’t know anybody that had gone through this especially at such a young age.”*

Sunny described how people have difficulty distinguishing normal forgetfulness from younger onset dementia. *“You know if you forget something, or whatever. I mean a lot of things with early onset is that people attribute it to, you never concentrate, or he never remembered things anyway. You know, Mom always did that anyway.”*

Rose revealed her hesitancy in telling others about her husband's diagnosis, despite the presence of significant changes in her husband's behavior. She said, *"I just started telling them this year."* She expressed her feelings about adult day care programs:

So it seems like it's all older people. I think if I ever brought him (her husband) to a social gathering with all these people in wheelchairs and walkers, he would run screaming out of there. As would I, I think.

Unlike the other participants, Minnie expressed relief at the diagnosis of younger onset dementia. She said, *"You know at that point, I was like, thank God it's not a brain tumor. Thank God it's not cancer. I'm like you're still my husband."*

Everything Looks Okay to Others

All of the participants shared examples of how differently others see or don't see the changes in the person with younger onset dementia. This often prompted feelings of isolation and sometimes anger.

Jane described her husband's ability to hide his cognitive changes and her family's view that her husband acted like he always did.

Sometimes, like in the beginning they'd be like maybe he's just faking it. Because he was so on key. My family doesn't see it sometimes because I think he rallies so hard. My sister just had a graduation party and he removed himself with the excuse that the Mets game was on and he asked if he could watch it in the living room.

Jane described her girlfriend's disbelief about her husband's change in behavior until she witnessed an angry outburst for herself. Jane explained what happened.

When my husband had his anger outbursts in the beginning, I was telling my girlfriend and I don't think she believed me. One day she came over and he didn't recognize her and started on a tirade, like he didn't know it was her. She was like, oh my God you're right. I was like, I've been telling you this, why didn't you believe me? But when you see it, then all of a sudden you understand it.

Lynne relayed a very similar experience. She explained, *“People would talk to him and they wouldn’t realize anything was wrong with him until you got into a conversation. Then all of a sudden, it was like something is not right here.”*

Lynne continued to describe her sister’s perception. She said, *“My sister was funny because she would see him, and I would say things, and she would say he seems fine. I don’t know what you mean. He seems fine, he looks good, and he is talking.”*

Patty shared a similar sentiment that others do not always recognize changes in her husband. She felt her experience in the healthcare field enhanced her ability to perceive the subtle changes in her husband’s behavior.

They look at him and sometimes, I have that little card that says he has Alzheimer’s because if you are not in the field like I am, you don’t know there is something wrong with this person because he looks okay. His eyes are just not really with you.

Rose expressed her feelings when she said, *“It’s just very upsetting because if you sit with him for an hour or two and socialize, he seems to be doing great. It drives me crazy.”*

Minnie clarified her view that it is hard for anyone else to notice the changes in her husband’s behavior because they are not with him for extended periods of time. She said, *“But nobody else could notice it in the beginning because nobody else lived with it.”*

Patty described another example of how things look differently to others.

In fact, my neighbor down the hall, who’s known us for a long time said, “He always knows my name. I thought he was doing fine. And they don’t know what you’re going through. He looks great to them. Yeah, well he does, I worked on him. He looks wonderful. I look dreadful. People just don’t really want to believe it.

Woody stated simply, *“Sometimes people assume that things are okay.”* This was another example that elucidated that others have difficulty discerning the subtle variations in behavior associated with younger onset dementia.

Sally described how her husband’s co-workers reacted to his forgetfulness. She said, *“He told me when he asked his co-workers if they noticed he was forgetting things, they would be like, no buddy, and you’re fine.”*

Doris explained mixed reactions to her husband’s behavior. She said, *“Half the population down here thinks he’s fine, and the other half are like, call the police. I’m like are you kidding? He folds clothes for 14 hours a day on the dining room table!”*

Sunny portrayed her assessment of the ability of friends to detect the insidious changes in her husband’s behavior. *“Most of our friends would not know he had it.”*

Spouse’s Perception of Self

Some participants voiced feelings of isolation related to their partner’s lack of insight into their changes. The majority of participants described situations in which their spouses with younger onset dementia denied that anything was wrong, frequently accusing their spousal caregivers of over-reacting to their memory lapses or changes in behavior. In some instances, the participants expressed relief that the affected spouse didn’t recognize the significant decline, saving them from embarrassment and shame.

Doris pronounced her sentiment that she was thankful that her husband was not aware of changes, especially with his lack of attention to his physical appearance and personal hygiene. She said, *“I’ll say to him, you would die if you saw yourself. He thinks he is fine by the way.”*

Jane described how her husband notices changes in other participants in the day care program he attends. She said, *“He notices differences in other people. It’s a little hard because I’m not sure how to address that. But he will tell you, he’s got dementia but he is better now.”*

Rose conveyed the sense that it was actually easier for her husband because he was not aware of his deficits due to his loss of short term memory. She stated, *“In a lot of ways, I think it’s easier for him because he doesn’t remember.”*

Patty differentiated how she views her husband as a child, but he still sees himself as a husband. She declared, *“He sees himself as an adult, but I don’t.”*

Woody described how her husband’s lack of insight affected his behavior, especially his resistance to help with personal hygiene.

And that’s why he gets mad because he thinks he can drive. He thinks he can go right out the door and he probably could. No husband wants his wife to sponge bathe him, no husband wants his wife to talk to him like he is five years old. I don’t care what anyone says.

Theme 6: The Struggle to Survive

Caregiver Needs

Woody used the following analogy to stress how important it is for caregivers to take care of themselves, offering the following advice for other caregivers.

And take care of yourself. It’s like the whole thing in the plane and the oxygen. You put it on first, because you can’t take care of that person if you can’t take care of you. You’ve got to take care of you because you are the advocate. I realized I was his advocate because he can no longer speak for himself.

Woody verbalized the realization that not only did her husband need an activity but she did too. She explained:

As time went on, I knew he needed a program and I needed something. He was just sitting there getting restless, we needed to do something. It's taken me some time to get it in my head that's it is okay if you enjoy yourself.

Rose offered a different perspective regarding her decision to continue to care for her husband. She stated that she told her husband:

You know I can walk away any day and live very comfortably without dealing with you. It's my choice to stay. I'm definitely not a goody two shoes, I'm definitely not Mother Teresa. But I feel like in five years' time or however long any of this takes, I want to be able to say I did the right thing.

Rose stressed the need to ask for help, although she encountered challenges in getting assistance from her husband's family. She voiced mixed feelings about continuing in the caregiving role:

I would say don't be afraid to ask for help. Try to get family members involved. Probably won't work. But try. I didn't say do you think you can help. I just said, "I'm out" and someone else is going to have to step in here. Basically, I told them, I am no longer pretending that everything is fine here. Things are not fine. They are the opposite of fine and I honestly don't know if I can go on. So if I do step away from this, I want everyone to know that it's not because he is sick.

Sunny spoke about her work role as helping her continue as a caregiver. She said, *"I love my job, that's where I get my rejuvenation."*

Patty described her need for affection as she talked about getting her husband to sit near her and hold hands.

I keep telling him. I have needs too. You're going to have to let me do it (hold his hand and sit close). So I sit here and I want him in here too. He tried. He came over and sat here for maybe three or four minutes and he said, that's it and went back to his own chair.

Patty explained how her husband's restlessness at night was affecting her ability to sleep at night, prompting her to take action. She said, *"Right now, I bought a bed for myself in the second room, figuring I would sleep there. I tried it for two nights and he kept coming in."*

Sally also depicted how lack of sleep is affecting her energy and ability to exercise. She explained,

I don't sleep because he asks me all night long what time it is. I quit the gym because I'm too tired to get up because I'm up all night long. He constantly wakes me up to ask, "Who's sitting over there?" or "Why are there spiders on the ceiling."

Doris described how coming back up to New York State to be with family and friends has affected her health. She said, *"I probably gained ten pounds. I drank more. I'm exhausted. I'm much more stressed in the last six weeks that I have been since this started."*

Rose referred to a vacation she took with some of her friends. She stated, *"After about the third day, I actually said this to myself, well hello. It was me again. I thought well that's who I am, I remember her."*

Patty talked about her own health problems.

See this wonderful weight. I can barely move and it's very scary to me. When I really have problems, I'm taking Xanax. I take Prozac. I take so many medicines. I take more medicines than he takes. So it's all stress and asthma. I don't think of myself first, which is very hard. Because frankly; sometimes I like to be curled up in a ball. I mean because sometimes I'm tired. Some days I do really well but then something will happen. I have to learn to reach for the Xanax, not food. I'm not exercising, can't do it.

Similarly, Woody stated, *"His blood work's great. Mine is generally not. He has high blood pressure but his blood pressure is better than mine."*

Sally succinctly described her life when she said, *"Just, you know, go to work, come home, but you know, no fun."*

Jane expressed her desire, *"I just want to be happy. All I keep saying is, why can't I be happy? Why can't this just go away and us just be happy? That's the hardest part. Not feeling happy all the time."*

Doris declared, *“I’m in quicksand. I’ll be dead before him. And I don’t have any time to tell you people, that this is killing me.”*

Lynne spoke about the barriers to self-care and attending to her own needs.

It was very hard to find any bits of time to take care of myself. I would have dinner once in a while with a friend, if I had someone to stay here with him. I couldn’t do the support groups because they were on a regular basis, like on a Wednesday night and there wasn’t anyone to be with him.

Many of the participants voiced the need for time alone. Sally described, *“He really doesn’t want to do anything, only with me. It drives me crazy. It’s always me.”*

Impact on Family and Friends

Jane described the impact on the couple’s three children. She said, *“It’s very tough on the kids because I don’t think they understand it and don’t want to.”* She was particularly concerned about their youngest daughter:

My youngest said, “If Daddy forgets my name I will kill myself.” It was a battle with her to go away to college because she thought he would forget her. My husband kind of zones out lately, in front of the television. Last night my daughter said to me, “Daddy doesn’t hear me. He is sitting right next to me and it takes a while for him to answer me.” She doesn’t realize that it’s part of the disease. I don’t know if I should keep saying it is part of the disease because I don’t want them to think that he’s horrible, like he’s doing this on purpose to them. And the only thing I can say is they’re blessed because now they can have a relationship with their father. Before he worked so much; they really didn’t have a relationship with their father. Maybe that’s the reason why these things happen, I don’t know.

Lynne described her daughter’s reaction to her father. She stated, *“She doesn’t visit with him. She kind of turned off to things quite a while ago.”* Lynne’s daughter did walk in and out of the room during the interview but never engaged in any dialogue except a perfunctory hello.

Lynne talked about her experience with her friends. *“You know people seem to fall away after a while. It’s the disease is too long. That’s how I put it. Some of my best friends, I don’t even speak to anymore.”*

Woody explained the impact on her daughter who has been actively participating in her father’s care.

It’s very hard on my daughter. She’s been here with me every step of the way. And to see her father who she loves, sometimes not know who she is? You know it’s very hard. I knew that there were times when she might not have done something because she didn’t want to leave me. She would sit with him so I can go to meetings and do things.

Rose described her stepdaughter’s reaction to changes in her father’s behavior.

She just burst into tears and said, “What’s wrong with my father?” I said do you really want to know? First, I told her about the alcoholism which he always kept under control in front of her. But then, I told her that he’s been tested and he has cognitive impairment and explained what that means.

Sally explained how getting a diagnosis alleviated some of the stress the family had been experiencing. She described her husband’s behavior, *“He would start a fight, then go upstairs and slam the door. Then we would be like, okay we can relax now. It’s better now that he’s diagnosed because we just thought he was acting like a jerk.”* Sally shared that she is not able to spend time with her grandchildren like she used to. She said, *“I used to go to my daughter’s every Thursday night after work. I would have dinner with them, play with the kids and put them to bed. I miss that a lot.”*

Minnie described how her family responded. She said, *“So we rallied as a family, together with our kids. We have two boys; they’re now 22 and 16. We just committed to just being at peace with where we are.”* She went on to talk about their youngest son:

My younger son has been home and been the brunt of it all. He doesn't show a lot of emotion but he's written a pretty poignant essay for a program that he was trying to get in to. So for him, it came out through his writing.

She concluded by admitting that other members of her family notice things that she doesn't see.

She said, *"My parents are even noticing it. My sister noticed it. I keep asking them, what do you see?"*

Tipping Points

As the participants expressed their struggle to survive, tipping points were frequently identified as examples of when things changed.

Sunny described a family vacation and what happened.

We had gone away camping upstate near Albany. I'm really good with directions. My husband wanted to go to Radio Shack. I gave him directions and he took our son with him. He was lost for four hours, could not find his way back. He stopped and asked for directions several times. It was a very stressful event. And I said, "That's it, when we go back you're getting tested."

Lynne described similar experiences with her husband's driving before he was diagnosed. *"He went to get dry cleaning and got a little turned around. It was dark out and he didn't know exactly where he was. We had to try and find him and luckily we did. He didn't drive after that."*

Woody communicated a story about a driving incident as well.

Well, I guess he was trying to do something and he put his foot on the gas instead of the brake. When I looked he had hit the side of the fence. I'm like, thank God the fence was there or he would have gone straight into the water. So after that I didn't have any problems with him driving. I was like, have to take that away from him because he just can't do it.

Being a passenger in a car proved challenging as well as Woody explained:

We were in the car on the LIE (Long Island Expressway), and he's pulling his belt off and on. I did it and he undid it. There was an extra connector on the seatbelt because he was so big. I had my hand on the door lock to make sure he didn't unlock the door. But he was like stop the car, I want to get out. I took him straight to the emergency room and they had to give him so much Haldol to calm him down.

Rose described what happened when the couple went on a vacation to Rome.

Anyway, on our trip to Rome, we filled out the forms for customs and I went to use the ladies' room. I came back and didn't give anything a second thought until we were getting ready to go through customs and I couldn't find my passport. I always put my passport in the same place! I was pulled aside and they were talking about putting me back on a flight to New York. All of a sudden, somebody comes into the room and tells me that your husband found your passport. It was in his bag, his carry-on bag. I was freaking out but once I got through I decided not to let it ruin our vacation. Knowing that this interview was coming up, I felt, wow, that was probably one of the first real signs that something was wrong.

Several of the participants spoke about loss of bladder control as a major tipping point.

Patty stated, *"My husband can't aim the urine. The urine doesn't always go in the toilet and he soils his pants. I bought diapers but I think he is too aware to do that right now. I just have them here in case we get desperate."*

Doris depicted a time when her husband went to put garbage in the trash room of their apartment building and got lost. She said, *"He couldn't figure out what floor we were on. So finally the building manager called me and said he's down here, he doesn't know what to do. So that's when we moved to the ground floor."*

Sunny described a time when her husband missed an important business meeting.

What do you mean you didn't go? He goes, "I couldn't find it." So that was a big wakeup call, like what do you mean you couldn't find it? He goes, "I just couldn't remember how to get there. I said, "Well, you have GPS in your car." Even that wasn't a signal to me because he was never really good at figuring that kind of stuff out. But that's when it started clicking. Like you can't even figure out how to get there and he'd been there before. It wasn't like a new place.

Woody depicted a scenario in which her husband lost his cell phone, a trigger that she needed to be around more:

He had a cell phone and then all of a sudden, he couldn't find it. I'm looking, I'm looking and tearing everything apart, looking, looking, couldn't find it. So I went and got him a new one. And one day my daughter says, "Mom you're going to find that phone." One day I was making the bed and I happen to lift up the top part of the mattress. He had put the phone in between the mattress and the box-spring. So that's where I found it. That's when I knew I had to stop working.

Safety Concerns

As the participants spoke about safety issues, the discussions included concerns for the safety of the spouse with younger onset dementia as well as for the people they interact with.

Jane illustrated this theme with the following story:

I went out to pick up pizza. I come back, my daughter's in a towel at the front door. She called the police on him (her husband). We live in a mother/daughter house and I guess his mother said something to him that set him off. He went upstairs and started throwing things off the deck. My daughter thought he was going to jump off the deck and kill himself, so she called the police.

Jane spoke about another incident that prompted her to seek medical treatment. She explained:

Within two weeks, he was crazy again. I brought him to the hospital, where they told me they would just drug him, it they took him in. At that point, I'm afraid for my kids. I said to him, "We have to go to the hospital, you're scaring me." I told the doctors I don't care, I'm afraid of him, you need to do something. He was there for three weeks until they got his medicines okay. He's home and seems to be doing very well.

Doris described what happened when the couple went out to a restaurant. She said,

Let me just go to the bathroom, I'll be right back. I come out and I don't know where he went. I never worried about that before. But I realized I started him on Seroquel just two days before. So I had to call the cops and that probably aged me another ten years because I can't believe I have to do this. It's four o'clock in the afternoon. I'm like, I'm not worried about him, but I am worried about if he runs into a school bus.

Minnie expressed the need to have others help keep her husband safe.

Because I need to have people help me. Even my kids, I'm like we have to be in this together. If we're not in this together, then we can't help him. We can't be aware of things that could potentially be harmful or dangerous, if we don't have a lot of eyes on this.

Sunny described the important role of her neighbors in looking out for her husband's safety. She said, *"Everybody knows (about her husband's dementia) especially in the neighborhood. So if he's out, I feel comfortable if I ever needed to call anybody and say have you seen him?"*

Woody depicted strategies used to prevent her husband from wandering and getting lost.

Matter of fact, my daughter got a lock on the screen door where it locks inside and we put the key where we knew it was but he didn't. So he could try and try but he couldn't get out. He could open the inside door but he couldn't get through the screen door.

Safety and driving was a concern voiced at different times by all nine participants. Lynne captured the overwhelming fear when she said, *"I was afraid for him, I was afraid for people on the road."*

Rose described what happened when her husband went to visit his brother in North Carolina, traveling on a plane by himself. She had made all the arrangements and depicted what occurred the day of his return. She arrived at the airport to pick him up and couldn't find him.

I think, oh God what happened. I know he checked a bag. So I go to baggage claim, I'm standing there. I see his bag on the carousel but I don't take it because I know I might be in the airport for a while and I'm not dragging this thing around. I text his brother to tell him he wasn't on the plane. His brother said, "What, I dropped him off." I asked to check the plane and after telling them that he has Alzheimer's, they are able to check and find out that he missed the plane. The airline staff got him on the next flight. I wish I could chip him.

Facing Changes

Part of the struggle to survive expressed by the participants was the ability to recognize and make meaning of changes occurring in their lives.

Woody relayed a moment of revelation. She said, *“It really hit me on New Year’s Eve, he was still in respite care and I went to the church service. I realized I’m going to be doing a lot of this stuff by myself from now on.”*

Rose stated bluntly, *“You can’t put frosting on something that’s not a cupcake.”* Rose continued to explain how she was dealing with several things at once; alcoholism, infidelity, and her own health issues. She declared, *“This doesn’t happen in a vacuum in anyone’s life.”*

Patty described how she noticed physical changes in her husband. She explained, *“You can tell by the way he moves and the way he acts, that there’s something different. But you wouldn’t have been able to tell that when we first moved here.”*

Doris explained strategies she used to deal with changes in her husband’s behavior. She stated, *“I keep everything calm, everything soothing, but I have duct tape on certain doors.”*

Theme 7: Navigating Day-to-Day

The final theme revealed in the analysis of the participant’s data was how each of the participants described the ways that helped them in their daily lives. This included coping strategies as well as philosophical perspectives. The first sub-theme is depicted as living in the present.

Living in the Present

Rose explained her philosophic view. She said, *“I try to remember that I have a very limited time with him. So I do travel with him. We have spent money. Everybody’s like hoarding and I think what are we waiting for?”* Rose offered some practical advice for other caregivers. She suggested, *“One thing would be to take one day at a time. Not to try to project too far out, without sticking your head in the sand and ignoring things, like legal things have to be dealt with.”*

Lynne echoed a similar sentiment when she stated, *“Just live, just keep on living. Because if you live all consumed by it (prognosis of dementia), that’s all you do.”*

Patty explained her viewpoint. *“I think it’s harder when you know what’s expected. It’s better when you don’t know. You can enjoy the present a little bit more.”* She went on to say, *“Mostly don’t look ahead, live in the present and enjoy what he can do today.”*

Sunny described a strategy that works for her and her husband. She said, *“I mean for me, I’m working every day. I work crazy hours. A lot of times I’m home in the morning and we usually read the paper together and talk about it.”* Sunny explained her rationale for living in the present:

Well, I’m sure for me there’s a lot of denial in there. I’m not going to that place at the end. I’m just not going there because I’m well aware of what could be in store. So I enjoy where he is now and the reality is there’s no guarantee, you know?

Adult Day Care

Although, adult day care was very helpful for some of the participants in managing their daily lives, it was often fraught with mixed emotions for the caregivers whose spouses attended adult day care programs.

Woody described her initial reaction, *“I couldn’t see him in an adult day care program.”* She had experience working with nursing home patients and older adults and felt her husband would not fit in due to his younger age of 61.

Patty explained her mixed emotions about bringing her husband to adult day care, *“It was very hard for me at first. It’s a beautiful place. They are loving, and he’s very happy; never objected to going.”*

Sally conveyed her feelings as well as her husband’s perception, adding the additional concern about cost of the day care program.

I just wish that they would have something for younger people like the doctor told us about. I don’t know of any programs for younger people with dementia. If he went with people his own age, he might go, but I can’t send him to a place with all old people. He’s picturing a bunch of old people. If I couldn’t afford it, I wouldn’t do it.

Doris communicated a comparison to her 97-year-old mother. *“He doesn’t belong in a system with people like my mother at 97 years old playing Bingo, he just doesn’t.”*

Minnie described an experience with an adult day care program. *“He did go to one program. We just left because it was too depressing. It was almost like, here’s your future, when you don’t even know what your future is going to look like.”*

Lynne shared the barriers to accessing adult day care for younger adults with dementia. She said, *“I started investigating if there was any place that he could go. The first place I called, said he had to be 60 (he was 58) and they told us to call back in two years!”*

Support Groups

Five of the nine participants in this study attended support groups for caregivers of persons with dementia. Their perceptions are presented in this section.

Jane spoke about her experience. *“If you go to the Alzheimer’s Association, most of the support groups are for older people.”* Despite this limitation, she went on to convey the benefits, *“And the resources, finding the resources. If I didn’t go to the dementia support group, I wouldn’t know about community Medicaid and being able to keep him home, if possible with an aide. There’s no information.”*

Woody had been active in support groups for several years. She explained, *“I joined a support group for spouses and I’ve been going to the group ever since. I joined a support group for all caregivers, whether you are caring for your mother, brother, sister but it’s a little different when it’s your spouse.”*

Lynne described her feelings about support groups:

I have a little problem with support groups because I feel like that’s all they talk about. And my daughter is the same way too. We felt a little like we were not good people. Everybody was saying but you have to be this way and you have to be certain (inaudible). There were times we wanted to say, “Come on. Wake up. It’s hard for everybody. It’s not that easy to just say you know it’s (person with dementia’s behavior) not on purpose.

Sally spoke with frustration about advice to attend support group meetings. *“Clients and people at work ask did you join a support group. I find it kind of annoying. I’m like when would I go? He’ll get mad if I go.”*

In contrast to Lynne’s perception of support groups, Patty discussed guidance she received from other support group attendees. She said, *“I met with my support group and they said travel as much as you can while you still can. What did I get from that support group; a lot of comfort.”*

Sunny described her experience, *“It’s interesting, I’m listening to how other caregivers are coping but you want someone who’s going to understand you, what you’re going through*

and you need to feel comfortable saying something stupid like, guess what I found him doing today.”

Doris was the only participant who had experience with using an on-line support group since she found it difficult to get out and attend meetings in person:

That’s why I’m on this Facebook support group. It’s a caregiver group for FTD (frontal-temporal dementia), primary progressive aphasia and other dementias with younger onset. Everyone’s kind of in that same age. So the scary part is we started two and a half years ago with about 79 people and we were talking the other day and now there’s like 910.

Ways of Coping and Support from Family and Friends

Jane described her struggle to find employment after being an at-home mom for so many years and how her brother helped. She said, *“Even the (employment) agencies told me you’re not going to get a job. So my brother funded me to go to a business school for coding.”*

Rose talked about how she eventually got support from her husband’s family.

He has a brother in California and I thought he could have been a little more involved. Anyway to make a long story short, we had a conference call with the family and he agreed to pay for an agency to do the applications (for Medicaid).

Woody spoke lovingly of the support of her friends. *“I have two very good friends and one especially, I would call and cry and talk to her and she never backed away. Because some people just don’t want to hear it. But she was always there and still is always there for me.”*

Rose described the support she found in her book club.

In my book club, I met another woman whose husband was a firefighter like mine. I asked if maybe her husband knew my husband. She looked at me and said, “He won’t remember, he has Alzheimer’s.” And I looked at her and we kind of bonded at that moment. We have a new friendship.

Sunny explained her source of support as being from her children, neighbors and co-workers.

I've been lucky that even though the kids aren't around constantly, they're here in the house. I can go to work comfortably. My neighbor comes by every day with her dog and they go for a walk every afternoon. But I need to rage and I can't do it around him. So I have friends that, you know, I can do it to. My co-workers are phenomenal; I'm in a field (health care) with a bunch of people who get it.

Patty described a bit of disappointment with support from friends, stating:

I tend to think people don't associate with you as much even though they say call whenever you need me. I used to have people calling me all the time. Friends were calling me every day. That doesn't happen so much anymore. It's not their fault."

She continued to explain a spontaneous, unexpected source of compassion:

All of a sudden, I feel arms around me and it was my granddaughter giving me a hug. It was such a weird feeling that makes me still remember that moment. It was just the right thing to do. She didn't say anything. She was just there.

Doris spoke about the support she received from her employer. She depicted, "And he said, "I know I can't change it, I can't buy it, and I can't fix it. But I know if you're asking me for help then you need help". He's the one person I can count on."

Doris expressed bitter disappointment as she described an interaction with her mother-in-law:

You can move in. I am like, please you know I need help. Move in, I'm happy to have you. I set up the house and built it that way, the condo was restructured to be comfortable for you. All of a sudden the phone rings at 9:30 at night and I see it's her house phone. She goes, "I can't do it." I said, what? She said, I can't see him. I said, what do you mean you can't see him? She's like, I can't watch it.

The support from children was a thread throughout the interviews with each of the nine participants. Several excerpts will be used to focus on this aspect of support.

Sunny described how her son helps. She said, *“He’ll surprise me and take his Dad on an outing. He’s great when I ask him to take his Dad to appointments. So if he’s not working he’ll help out with that.”*

Patty described her daughter’s intuition about when she is having a bad day and how her children rally around her:

So I had a problem the other day and I was really, really depressed. So I couldn’t talk to my oldest daughter. About two hours later, my youngest daughter called to find out how I am and I said. “I can’t talk right now.” She said, “Yes you can.” And so she talked to me. She said, “I don’t care, turn off the television, walk out of the room, and talk to me.”

Woody expressed concern for her daughter. She explained, *“I share everything with my daughter. She is here. But I feel bad because she needs to live her life. This was not what she signed up for. I am the one married to him.”*

Work Outside of the Home

Six of the participants were currently employed outside of the home for the financial security of their families. However, many of the participants voiced the additional positive impact of working on their personal ability to manage the challenges of their caregiving role.

Jane explained, *“I work in an outpatient rehab, it’s a lot of young kids, there’s older people too. I just feel like I’m needed so it helps me to feel good about me.”*

Sunny described how work helps her cope. She explained, *“That’s the frustrating part of this disease is that you don’t know how fast or how slow or what things are going to go first. That’s why thank God, I am working.”*

Minnie admitted, *“I work a lot.”*

Patty lamented when she stated, *“I really loved working.”*

Strategies

A variety of methods were used by the participants to cope with unique situations.

Woody described the use of music as a calming technique:

He likes music. So if we were watching something on television and he was starting to get agitated, we would turn it off and put some music on. There were certain programs that he liked so would DVR them and then play them. There was one music CD he really liked by the Stylistics. So we would play that over and over again. It calmed him down. I would just tune out the world.

Sunny talked about the positive influence of a little humor:

You know, he jokes around, we all do. We kind of make it like, making fun of things, sometimes with him to laugh at him and laugh at ourselves kind of thing. So it's not so much I'm getting frustrated. Because my older son would get more frustrated.

Sunny shared how she manages her reactions to challenging situations. She further shared, *"I don't freak out about it and if I don't freak out, they (her sons) don't freak out. I make sure I have somewhere else to go when I'm upset."*

Patty announced, *"I try to keep myself busy. There's something planned for every day."*

Sally admitted, *"I'm much happier when I'm not home. He drives me crazy."*

Doris described a unique approach to dealing with challenging behavior. She explained, *"I videotape, I blog. Because I just can't believe that he'll yell about things like not wanting me to move the suitcases. I have to do things in the middle of the night, not that he really ever sleeps."* Doris proclaimed, *"We can go to three movies a week, that's five hours of downtime for me."*

For some of the participants exercise served as a very positive coping strategy.

Minnie stated, *"I work out a lot."*

Doris talked about running:

I run in the morning. It's my only hour of sanity. People say they see me running on the boardwalk, you seem so focused. I'm like no that's because I'm listening to my playlist and I've got like 35 minutes. They're like what do you mean? I'm like, I'm not thinking about things, for what? They go how do you do that? I go, how can I not do that? I think one of the best things that's happened to me is I have the ability not to be able to think. It's a roller coaster that you're never going to get off. There's never a good day. There just isn't.

Minnie explained how maintaining a sense of control is important to her:

I'm a very in control of the situation type of person. After we got his diagnosis, we were just like okay, we're going to get disability and we're going to change this and we're going to do that. And then I felt in control. Right now, I feel in control and confident about myself, about my future, about my children's future but I don't know what's going to happen to him (her husband).

Jane admitted, “*Sometimes I scream and yell, which I feel guilty about.*” She explained how she gets her husband to take his medicine. “*I mean there were a couple of times when he hadn't taken it for two or three days. I'd finally say, “If you can't do it for me, do it for your children. And then, he'll take it.”*

Patty talked about how the dementia has affected her relationship with her husband and how things have changed with how he interacts with their grandchildren:

We enjoyed our grandchildren, I mean they're fun and they're all on the floor and there are pictures of him on the floor with the kids rolling on the floor with him. But now he barely interacts with the kids. He gives them a kiss hello and that's about it.

Conclusion

The seven emerging themes derived from the transcribed interviews of the nine participants in this study illustrate the meaning of the lived experience of relationship transition in significant others caring for a partner with younger onset dementia. Table 6 provides a summary of the themes, the sub-themes and summative descriptions of the higher formulated meaning for each of the seven themes.

Table 6

Emerging Themes and Sub-themes

THEMES	Sub-themes	HIGHER FORMULATED MEANINGS
The Way it was Before Dementia	<ol style="list-style-type: none"> 1. In the Beginning 2. How it is Now 	Caring for a spouse with younger onset dementia has a significant impact on a couple's relationship. Relationships described as close and loving prior to the onset of dementia may be helpful in the transition that occurs as spouses assume more caregiving responsibilities.
A Maze of Uncertainty	<ol style="list-style-type: none"> 1. Why is this happening? 2. Getting a Diagnosis 3. Interactions with Healthcare Providers 4. Things are Constantly Changing 	There is a distinct influence of the concept of uncertainty across the trajectory of caring with a partner with younger onset dementia. Discrete sub-themes serve as a source of confusion, anxiety and as a barrier to understanding what is happening. This limits the ability of the caregiving partner to enjoy the present and/or plan for the future.
A Kaleidoscope of Feelings	<ol style="list-style-type: none"> 1. Anger 2. Overwhelmed 3. Guilt 4. Frustration 5. Embarrassment 6. Fear 7. Hope 	Diverse emotions exist simultaneously and are triggered by the behavior of the person with younger onset dementia as well as the demands of assuming the role of caregiver.

Shattered Dreams/Expectations	<ol style="list-style-type: none"> 1. Role Change 2. Loss of Couplehood <ol style="list-style-type: none"> a. Loss of Partner 3. Loss of Financial Security 4. Changes in Intimacy 	Multiple losses characterize the lived experience of spouses caring for a partner with younger onset dementia. An overarching element is the alteration of the couple's anticipated future.
A Solitary Journey	<ol style="list-style-type: none"> 1. Stigma of Younger Onset Dementia 2. Everything Looks Okay to Others 3. Spouses Perception of Self 	Caring for a partner with younger onset dementia is an intensely personal experience guided by personal values and a sense of moral responsibility. A sense of being alone on this journey is a common feeling among spousal caregivers.
The Struggle to Survive	<ol style="list-style-type: none"> 1. Caregiver Needs 2. Impact on Family and Friends 3. Tipping Points 4. Safety Concerns 5. Facing Changes 	There are many factors that impact a spouse's ability to successfully negotiate survival when caring for a partner with younger onset dementia. Internal fortitude, perseverance, taking care of their own needs, problem solving skills and recognizing the impact on themselves and others provide a framework for a meaningful caregiving experience.
Managing Day-to-Day	<ol style="list-style-type: none"> 1. Living in the Present 2. Adult Day Care 3. Support Groups 4. Ways of Coping <ol style="list-style-type: none"> a. Family and Friends b. Work c. Strategies 	A variety of coping strategies support spousal caregivers in managing the daily lives of their spouses as well as their own. Limited resources are a specific challenge for spouses caring for a partner with dementia.

Chapter five includes further discussion of the overall findings and limitations of this study, implications for healthcare providers and social policy decision-makers, and recommendations for future research related to the topic of this study.

Chapter Five: Findings

Summary

This study illuminated the experiences of nine wives caring for husbands with younger onset dementia. The cognitive, psycho-social, and functional changes that occur as a result of younger onset dementia place a considerable strain on a couple's relationship. While these changes are present regardless of the age of the onset of the dementia, it is particularly stressful when these changes occur at a younger age. Data from the interviews provided an opportunity to view the lived experience of significant others caring for a partner with younger onset dementia through their unique lens. Enlightenment regarding their perceptions may lead to the development of ways in which healthcare providers can support and guide couples facing relationship transition when confronted with younger onset dementia.

Links to Theoretical Framework

Transition Theory

“Vulnerability may be conceptualized as a quality of daily lives uncovered through an understanding of client's experiences and responses during times of transition (Meleis, Sawyer, & Im, 2000, p. 12).” According to Meleis and colleagues (2000), nurses are often the primary caregivers of clients and families experiencing transition. The focus of this study was relationship transition in significant others caring for a partner with younger onset dementia. Meleis et al. (2000) discussed studies that illustrated the complexity of the experience of transition, noting that caregivers may be experiencing multiple transitions. This section will

provide insight into the correlation of the experience of the subjects in this study with Meleis' middle-range theory of transition.

“Transitions are both a result of and result in change in lives, health, relationships, and environments (Meleis et al., 2000, p. 13).” She identified the essential properties of transition experiences as, awareness, engagement, change and difference, time span, and critical points and events. Each of the properties of transition will be related to the insights of the significant others caring for partners with younger onset dementia interviewed for this study.

Awareness

“Awareness is related to perception, knowledge, and recognition of a transition experience (Meleis et al., 2000, p. 18).” It is depicted as an important property of transition. In the findings of this study several factors contributed to impaired awareness of the relationship transition. The majority of the participants noted changes in their spouses but attributed the changes to other causes, such as alcohol/drug use, stress, and lack of interest in the relationship. There was an awareness that something was happening, but for an extended period of time, it was very unclear what was causing the changes. Several of the participants felt that the changes might be temporary and that things would eventually go back to normal. The ability for the participants to be aware of the transition in their relationships was impaired by the uncertainty of the cause of the changes in their spouses. Lack of awareness, however does not prevent the transition in a relationship (Meleis et al., 2000). All of the participants experienced relationship transition but there was some variation in the level of awareness that was present.

Engagement

Engagement is defined by Meleis et al. (2000) as the degree to which a person exhibits involvement in the processes inherent in the transition, such as seeking out information, using role models, actively preparing, and proactively modifying activities. The participants in this study were all looking for answers as to why this was happening to their spouses; they were often unable to get adequate answers from healthcare providers. Role models were not readily available, even when a diagnosis was reached. The participants expressed the challenges they encountered searching for support groups that were designed to meet the needs of significant others dealing with younger onset dementia. Some of the participants admitted to denial and avoidance when faced with the changes that were occurring in their partners. For example, Minnie admitted to working longer hours and traveling for work as a way to avoid going home and dealing with her husband's behavior. Rose's engagement in the transition in the couple's relationship was overshadowed by her husband's alcohol abuse. Overall, there was a high level of engagement in seeking a diagnosis, especially as changes became more evident over time.

Change and Difference

To fully understand a transition process it is necessary to uncover and describe the effects and meanings of the changes involved (Meleis et al., 2000, p. 19).” The properties of change and difference are similar but distinct properties of transition. All of the participants in this study, experienced changes in their relationships with the insidious onset of the symptoms of dementia in their spouses. “Change may be related to critical or dis-equilibrating events, to disruptions in relationships, routines, or to ideas, perceptions, and identities (Meleis et al., 2000, p. 20).”

The concepts of change and difference were present in the relationship transition described by each of the participants in this study. In particular, as caregiving responsibilities increased, the participants expressed feeling more like a parent than a spouse. This change in role frequently impacted the caregiver's interest in intimacy. A lost sense of identity was noted as some participants struggled with disillusioned expectations of what their lives would be like at this stage of life. Woody described the loss of being a couple and the dream of growing old together. Rose described how a respite from caregiving allowed her to remember who she was before becoming a caregiver. Several participants had to return to working outside of the home, and one had to take a leave of absence from a job that she previously enjoyed.

Time Span

“Transition is characterized by flow and movement over time (Meleis et al., 2000, p. 20).” The flow of transition is associated with an endpoint. However, that may not be the case in certain types of transition. “Long term transitions are constantly in a state of disconnectedness, flux, or change (Meleis et al., 2000, p. 21).” The impact of time span is very applicable to the experience of the participants in this study. The unpredictability of disease progression and unclear timeline has a significant impact on the flow of relationship transition in couples dealing with younger onset dementia. Participants expressed the knowledge that their relationships would change over time, but also the hope that it might not happen for a very long time.

Critical Points and Events

According to Meleis et al. (2000), most transitions involve critical points or events. “Critical points are often associated with increasing awareness of change or difference or more

active engagement in dealing with the transition experience (Meleis et al., 2000, p. 21).” The relevance of critical points and events is illustrated in the emerging theme, the Struggle to Survive, in Chapter Four. These were described as tipping points, and were often related to symptoms displayed by the spouse with dementia that could not be ignored. In several instances, the escalation of symptoms prompted hospitalization to manage behavioral symptoms.

Issues of safety were prominent, including unsafe driving performance and inability to follow directions. There were several descriptions of the partner with dementia getting lost, resulting in frantic searches to find them. There were abundant descriptions of safety concerns that conveyed the impact on the trivial events in their day-to-day routines, such as cooking, locking doors, and the freedom to leave the house to do grocery shopping.

Critical points and events were noted to be very stressful for the participants in this study. Meleis et al. (2010) noted that caregivers are vulnerable during critical events and may encounter difficulty with self-care and caregiving. This was evident with all of the participants in this study as they expressed the lack of time to care for themselves overshadowed by a sense of guilt that prevented them from taking care of themselves. A few of the participants expressed concerns about their own health, such as gaining weight and not being able to exercise.

Integration of Findings with Previous Literature Review

The literature review for this study included nine studies which focused on caring for a partner with younger onset dementia compared to thirteen studies on late-onset dementia, and thirteen studies that included both younger onset and late-onset dementia sufferers and caregivers. The themes which emerged from this study shared some common threads with selected studies in the literature review and revealed several findings not found in the review of

the literature conducted for this study topic. The commonalities and dissimilarities will be described.

A recent report from the Alzheimer's Association noted that two thirds of dementia caregivers were women who tend to spend more time care giving, assume more care giving responsibilities, and are more likely to care for someone with a greater number of behavioral problems (Alzheimer's Association, 2017). The participants in this study reported similar care giving experiences in their descriptions of their caregiving tasks, the time spent on caregiving, and the challenges with behavioral issues in their spouses with younger onset dementia. Characteristics of the participants in this study were similar to recent statistics reported by the Alzheimer's Association (2017) regarding educational level, ethnicity, and employment outside of the home while providing care to a partner with AD or another type of dementia.

Comparable to the findings in a study conducted by Ascher and colleagues (2010), the findings of this study revealed that behavioral symptoms had a significant impact on caregivers' relationship satisfaction. Ascher et al. (2010) reported that significant others caring for a partner with frontotemporal dementia reported less marital satisfaction and used more negative emotion words. This was reported to be associated with the prevalence of behavioral symptoms in individuals who have frontotemporal dementia. The mean ages of caregivers and patients was under 65 in the study conducted by Ascher et al. (2010), while the mean age in this study was 59 for the caregivers, and 62 for the significant others with younger onset dementia. In both studies, data was collected at a particular moment in time and precludes longitudinal predictions due to the temporal nature of dementia symptoms, and the effect this may have on marital relationships. In this research study, several of the participants reported challenges with behavioral symptoms

regardless of the cause of the dementia; only one had been diagnosed with frontotemporal dementia. The participants verbalized that dealing with behavioral symptoms was challenging and shared stories that described the impact on their relationships. A similar finding in Ascher et al. (2010) was the reported dissatisfaction by the participants of this study with their partner's lack of empathy; subjects verbalized the loss of having a partner who expressed concern for the caregiver's overall well-being.

The focus on the loss of couplehood and loss of partner was a finding in the study by Forsund and colleagues (2014). Similarly, the participants in this study identified that loss of couplehood was a significant concern. However, in the Forsund and colleagues (2014) study, the spouses and caregivers were over age 65 and the loss of couplehood was primarily related to the spouses with dementia being placed in a long term care facility. This varies from this study, as the care recipients were all diagnosed with younger onset dementia under age 65, and all spousal caregivers were living at home with their spouses. While the concept was similar, the context of the experience was not; the loss of couplehood in the Forsund et al. (2014) study was attributed to loss of physical presence of the partner with dementia. The participants in this study described the loss of their partners and the impact on the identity of their couplehood, even though the affected spouses were still physically present in the families' homes.

The study conducted by Hain and colleagues (2014) used a descriptive phenomenological method similar to this study. Several findings, such as the need for tailored interventions and communication difficulties, mirrored the findings in this study. However, the focus of the Hain et al. (2014) study was on early stage dementia, not younger onset dementia, with mean age of the study participants being 79 years old. The temporal nature of the symptoms of dementia was

a commonality in both studies. The unpredictable course of dementia motivated participants to value living in the present. Participants in both studies, verbalized the heavy burden of being responsible for all aspects of daily living. Dealing with multiple losses was revealed in both studies as the disease progressed.

The longevity of care giving as a contributory factor in reports of increased caregiver burden/stress is consistent with findings reported in the study conducted by Arai et al. (2007). In the Arai et al. (2007) study, subjects completed two subscales of the General Health Questionnaire allowing for statistical analysis in subject reports of health concerns that may be related to caregiver burden. The length of caregiving for the subjects in this study ranged from 4-13 years. While this may be a contributory factor in the experience of the caregivers in this study, the data reported is subjective, provided in narrative form, and no statistical inference can be reported.

The NeedYD Study (Bakker et al., 2103) examined the use of formal and informal care for individuals with younger onset dementia. Bakker and colleagues (2013) reported spouses and family members provided most of the care; caregivers had the double burden of balancing work and care responsibilities, and access to formal services was related to disease progression. In the NeedYD Study (Bakker et al., 2103), 48.8 % of the caregivers were still working as compared to 55% in this study. They reported that caregivers of individuals with younger onset dementia delayed accessing formal care for the affected spouse until the advanced stages of dementia. The findings of this study were similar, however participants verbalized the lack of appropriate services available for individuals with younger onset dementia. They described

interest in services that specialized in meeting the needs of younger individuals with dementia, as well as frustration that most services were geared towards older adults.

A qualitative case from the NeedYD Study (Bakker et al., 2010) reported similar findings to this study regarding prolonged time to diagnosis, paucity of services for younger individuals with dementia, caregivers' struggles with role change, and disappointment in response and support from healthcare providers. The issues identified are specifically related to the caregivers' and care recipients' younger age and phase of life. Another common finding was the challenges of dealing with behavioral symptoms. The recommendations from Bakker et al. (2010) included the development of services that meet the needs of the caregiver and care recipient with younger onset dementia.

Literature Review after Data Analysis

This study adds to the existing body of knowledge regarding the experience of spousal caregivers of individuals with younger onset dementia. There were several findings in this research study that were not uncovered in the initial review of the literature for this study. Therefore, an additional literature search was conducted after data collection to seek information about the data analysis.

Work Outside of the Home

While many might believe that working outside of the home is a burden for caregivers, several of the participants in this study reported that working outside of the home helped them deal with the challenges of caregiving. Although all of the working participants verbalized the financial necessity to work to support their families, they also described the benefits of emotional support from co-workers, a sense of personal fulfillment in their work, a reduction in stress just

by being out of the house, and, in one case, an escape from facing what was going on at home. A review of the literature was conducted using the terms, work, work satisfaction, midlife women and baby boomer women. Many of the articles related specifically to the impact of menopause and associated signs and symptoms on the work life of middle-aged women. In addition, the focus was often on a specific profession/career such as nursing or state employees (Leggett, 2007; Wadsworth & Facer, 2016). There were no commonalities in the types of work the subjects in this study reported on the demographic form (Appendix C).

The focus on work-family balance for individuals in midlife years is a concern for employers especially with the increased presence of women in the workforce (Leggett, 2007; Wadsworth & Facer, 2016; Wright, 2005). “During midlife and its accompanying changes, thought processes turn inward as individuals seek meaning in life, clarify direction, and gain satisfaction (Leggett, 2007, p. 170).” It is interesting to juxtapose the “normal” expectations of role change in midlife years with the added context of caregiving for a spouse with younger onset dementia.

“Baby boomer women born between 1946 and 1964 have had more advantages than any other generation before them; they enjoyed expanded opportunities for higher education and professional achievement (Wright, 2005, p. 181).” She described the unique plight of baby boomer women who are working in roles previously held by men while also dealing with new technology, demanding work environments and the stress associated with caregiving responsibilities. According to Wright (2005), home stressors for midlife women are related to caretaking responsibilities for aging parents and children living at home; she does not include caring for a spouse in her definition. This supports the finding that the participants in this study

reported lack of understanding and empathy from family and friends regarding what it is like to balance life while caring for a partner with younger onset dementia. The midlife working women in this study depicted the positive influence of working, while dealing with the challenges of caring for a partner with younger onset dementia. However, this was frequently associated with less time for self-care as they attempted to negotiate work-life balance.

Role Change

For the participants in this study, role change was found to be a significant factor in their interest in sexual intimacy. Most of the participants expressed a decreased interest in sexual intimacy because they felt like “a parent caring for a child.” Only one participant, Sunny, described sexual intimacy as still being a positive component of the couple’s life. This may be related to several factors.

“Dementing illnesses can cause changes in sexual functioning that can have detrimental effects on the couple and their quality of life (Davies, Zeiss, Shea, & Tinklenberg, 1998, p. 202)”. This early study focused on the importance of healthcare providers including discussions regarding sexuality and intimacy in their interactions with individuals with dementia and their partners. The participants in this study expressed overall dissatisfaction with interactions with health care providers, but none of the participants disclosed discussions with their healthcare providers about sexuality and intimacy.

Physical changes related to menopause was verbalized by several of the participants as a contributory factor in their lack of interest in sexual intimacy. The participants tended to put the focus on themselves rather than on what was changing in their partners. Although behavioral issues were common, the participants did not disclose this as being associated with their

decreased libido. Since the literature for older adults describes the positive role of sexual intimacy in couples dealing with dementia (Davies et al., 1998; Harris, 2009), it was a surprising finding that the midlife women in this study did not report lack of sexual intimacy as a priority concern. A recent study conducted by Nogueira et al. (2017) was designed to examine sexual satisfaction in 74 dyads of individuals with AD and their spouses, and 21 elderly dyads as a control group. They found gender differences in spousal caregivers' sexual satisfaction. The authors reported that female spousal caregivers assumed different familiar tasks in their roles as wives, mothers, and lovers, reporting lower scores related to sexual satisfaction. This may be due to conflict in roles which negatively affects their interest in sexual intimacy with the spouse with dementia. While the findings by Noguiera et al. (2017) are similar to the findings in this research study, the mean age of all participants in their study was over age 65. Replicating the study conducted by Noguiera et al. (2017) in dyads with spouses with younger onset dementia may add to what is known about sexual satisfaction in the population of this research study.

Impact on Adolescent and Young Adult Children

Another observation noted in the findings of this study relates to the impact on adolescent and young adult children still living in the family home who are dealing with a parent with younger onset dementia. Six of the participants had children living at home, ranging from high school age to early 20's. Each of the participants described the impact on their children and overall family dynamics.

In a study conducted by (Panyavin et al., 2015), 102 caregivers of individuals with AD in Argentina were surveyed with scales measuring coping, family adaptability, general family functioning, and quality of informal care provided for the person with dementia. Panyavin et al.

(2015, p. 618) stated that “ in an effort to improve quality of care for patients with dementia, future interventions should target empathy and overall family functioning as important family dynamics constructs.” While this is applicable to the findings from this research study, it does not include the perspectives from the viewpoint of the adolescent and young adult children.

Several of the participants shared their perspectives about concerns for how their children were coping, and suggested including them in the interviews. Minnie shared an essay that her son wrote for a scholarship about his personal experience. She told me that her son’s essay provided her with a greater understanding of his experience of living with a father with dementia. He articulately described masking his feelings, taking responsibility for being the *man* in the house, needing to take care of his father on a daily basis, the stress of accompanying his father to doctor visits, and balancing school and social life. He poignantly ended the essay by saying, “*Being a caretaker also means taking care of yourself. Learning this changed my life.*” He is very perceptive.

Major Findings

A summary of the major findings is provided using the seven themes derived from the analysis of the data. The major subthemes serve as a framework for understanding the meanings of the lived experience of caring for a partner with younger onset dementia; emerging from the narratives of the participants in this study. The essence of their lived experiences is illustrated for each of the seven themes.

The Way It Was Before Dementia

Each of the participants described their relationships with their husbands prior to the onset of symptoms related to dementia. While these depictions varied, the reality of changes associated with younger onset dementia impacted the relationship for each of the participants in this study. Couples in midlife face challenges associated with multiple demands: work, aging parents, adult children, and their own physical aging. The changes associated with younger onset dementia disrupt how couples negotiate their roles as individuals and as couples. The impact of dealing with dementia at a younger stage of life does not, as one participant stated, “*occur in a vacuum.*” What clearly emerged was that things were different.

An interesting observation was that whether the relationship was described as positive, negative and/or both, the participants conveyed a sense of responsibility and loyalty in caring for their partners. However, it is important to note that the participants, who described their relationships as loving and close, used more positive language when speaking about their relationship transition after the onset of dementia. As the symptoms of dementia progressed and care giving responsibilities increased, it became harder for the women to remember the positive elements of the beginning of their relationships. Although this may be true in many long-term relationships, several of the participants speculated about the possibility that their marriage might not have lasted. Once their partner was identified as having younger onset dementia, ending the relationship was no longer an option in their eyes. A sense of commitment to their marital vows, moral and ethical values, and empathy for the affected spouse were driving factors in their decisions to continue as primary caregivers. Several of the participants voiced concerns that

family and friends may be critical of them if they “abandoned” their partners by deciding to place them in a long-term care facility.

A Maze of Uncertainty

Dealing with uncertainty is a ubiquitous component of the lived experience for significant others caring for a partner with young onset dementia. It begins with the insidious onset of changes in their partners which are often attributed to other causes such as substance abuse, depression, stress, possible infidelity, midlife crisis, and/or disinterest in the couple’s relationship. The journey to getting a diagnosis may be two to three years adding confusion and anxiety, serving as a barrier to understanding what is happening. Dementia is often not considered because of the younger age of the affected individual.

Healthcare providers were not perceived as knowledgeable or helpful by the participants in this study. Many of participants expressed that healthcare providers did not value their perspectives and were made to feel like they were the ones who were “crazy.” The breakdown of trust in the relationship with healthcare providers augmented the aura of uncertainty. This is very important and has strong implications for provider education and practice!

Lastly, the unpredictability of fluctuating changes in the partner with younger onset dementia impaired the ability for caregivers to enjoy the present and plan for the future. The only thread of certainty was that things would not stay the same, but what would change, and when it would happen, remained ambiguous.

A Kaleidoscope of Feelings

The visual image of a kaleidoscope depicts the constellation of the dynamic interrelatedness of the assorted feelings expressed by the participants in this study. The seven emotions that were expressed by all of the participants included: anger, overwhelmed, guilt, frustration, embarrassment, fear, and hope. The emotions do not occur in a linear manner and may exist simultaneously. Dealing with behavioral symptoms, escalating caregiving responsibilities, and lack of self-care contribute to the emotional roller coaster described by the participants. A sense of resilience was conveyed by each of the participants despite the expressions of dynamic feelings. An overarching message was the inability to have their voices heard. Feelings are interwoven like a tapestry in all of the emergent themes.

Shattered Dreams/Expectations

The theme of shattered dreams/expectations is characterized by the multiple losses expressed by the caregivers in this study. The most significant finding was the impact of role change on perception of couplehood, loss of a partner, and decreased interest in sexual intimacy. The participants described a role change from partner to parent. This was contrary to what each of the participants expected at this stage of the couples' lives together. Role change was exemplified by increased responsibilities for managing the family finances. For several of the participants this meant changing from being a stay-at-home spouse to seeking outside employment in order to meet the financial needs of the family. For most of the participants, assuming control of finances was critical to mitigate the loss of family resources due to mismanagement of money by the spouse with younger onset dementia.

The loss of a partner was expressed in a variety of ways. Some of the participants conveyed their partners' lack of empathy as a contributory factor. The participants expressed the loss of a partner who cares about their well-being, and in some cases, their safety. Several described that their spouses did not seem to be aware of their absences; while others felt that they couldn't escape from the constant need to be followed. In both cases, expectations of a supportive and caring partner were altered, leading to disappointment.

A predominant feature of this theme is the alteration in the couple's anticipated future as perceived by the caregiving spouse. The unpredictable course of disease progression and longevity of caregiving add to the disillusionment experienced by the well spouse caring for a partner with younger onset dementia.

A Solitary Journey

Isolation and a pervasive sense of being alone were conveyed by many of the participants. The first contributing factor is the lack of awareness that dementia can occur in individuals at a younger age. The lack of recognition by healthcare providers frequently caused a delay in getting a diagnosis. Friends and families were skeptical even when a diagnosis was made. This was complicated by the ability of many younger individuals with dementia to hide their deficits and thus appear "normal" to others. The participants expressed frustration and anger when they sought support from others, and felt that others did not believe them about their partners' cognitive and behavioral changes. The individuals with younger onset dementia often displayed a lack of insight into their mounting deficits. Several of the participants described feeling like they were the only ones who observed the changes in their partners, and as one participant stated, *"I felt like the enemy."*

Many of the participants expressed the burden of being the sole decision maker and an overwhelming sense of responsibility for all aspects of their lives. This was further complicated by the perception that others did not want to hear about their challenges, or that they could not bring themselves to describe their feelings to others. Several of the participants told me that one of the benefits of participating in this study was being able to express their thoughts.

The Struggle to Survive

Recognition of the need for self-care was a critical theme in the struggle to survive. All of the participants expressed the value of taking care of themselves, but described the challenges they encountered in finding the time and money to do so. Several of the participants expressed concerns about their own health; citing weight gain, increased alcohol consumption, lack of sleep, lack of time to exercise, and increased stress as contributing factors.

Living with an individual with younger onset dementia was reported to have a significant impact on relationships with family and friends. Some participants reported that friends avoided them and thus they experienced a loss of social interactions with others. The participants with adolescent and/or young adult children living at home expressed their concerns for how their children were coping with behavioral issues, as well as the loss of a parental figure.

Recognition of critical events that indicated concerns about safety was a key element in the struggle to survive. The inability of the spouse with younger onset dementia to continue driving a car safely was frequently identified after an event that resulted in getting lost and/or an accident. This was a significant change for several of the participants who were used to their husbands being the primary drivers in their families. Facing changes helped the participants in making decisions that promoted the safety of the individual with dementia, as well as others.

Navigating Day-to-Day

The focus of the navigating day-to-day theme was the variety of coping strategies used by the participants in this study to manage the daily lives of their families and their spouses, as well as their own. Several of the participants stressed the importance of living in the present. There was recognition that the path was unpredictable, and it was critical to savor the good moments.

The use of adult day care provided respite for some of the participants. Several participants verbalized an interest in adult day care programs for their spouses, but didn't feel that the services available were designed to meet the needs of a younger individual with dementia. This was a limiting factor in the use of adult day care services.

Support groups served as a source of information and emotional support for some of the participants. However, several of the participants reported a lack of interest in support groups and/or lack of time to attend. There were few support groups designed to meet the specific needs of significant others caring for a partner with younger onset dementia. Support from family and friends was frequently reported as a positive factor in coping with the challenges of caring for a spouse with younger onset dementia. This was depicted with examples of friends and family engaging in social activities with the spouse with dementia and in some cases "watching out" for their safety. Several of the participants spoke about emotional support and empathy from friends and family members.

The participants who were working outside of the home reported the positive support and encouragement they received from co-workers, a sense of being useful and needed, and respite from dealing with the challenging behavior of the spouse with dementia. While it was

challenging to balance work and home responsibilities, the participants reported working outside of the home as a positive aspect of their lives.

Implications of Findings

Nursing Education

The demand for dramatic restructuring in nursing education curricula is being prompted by evolutionary changes in the U.S. health care system and the increasingly diverse population which nurses serve. There are multiple factors that will affect the future of nursing in the United States; aging of the nation's population and the nursing workforce, new care delivery models in diverse healthcare settings, and changes in healthcare reimbursement and overall economic conditions (U.S. Department of Health and Human Services, Health Resources and Services Administration, Bureau of Health Workforce, National Center for Health Workforce Analysis, December 2014). Careful consideration of the settings in which nurses will practice, and the associated competencies required, is vital in the transformation of nursing education as we look toward training registered nurses for nursing practice in the next 10-20 years. Preparing nurses with the competencies needed to assist significant others caring for a partner with younger onset dementia is one of these necessary competencies.

The Institute of Medicine (IOM) Report (2010), *The Future of Nursing: Leading Change, Advancing Health* set the stage for transforming the role of nurses in the delivery of healthcare. This seminal report laid the groundwork for nursing educators to abandon the status quo and begin to develop educational models that will prepare nurses for the future. It is essential to

remain cognizant of the goal of nursing, to prepare nurses equipped to meet the health needs of society.

In order to prepare nurses to care for the vulnerable dyad of significant other and partner with younger onset dementia, nursing education must be considered at the undergraduate, as well as the advanced practice level. The first requirement should be the inclusion of the elements of the normal changes of aging. The basic understanding of how individuals change regardless of the presence of disease serves to help differentiate normal from abnormal. This is critical as the majority of nurses in all settings in the United States will be caring for older adults especially with the aging of the baby boomer cohort.

A focus on patient and family centered care is the current trend in the delivery of health care and, therefore, must be an integral component of nursing education. Nurses must be educated on nursing care delivery models that include the patient and family in the development of the plan of care. The plan must be based on the values and beliefs of the patient and family. Fostering an understanding of a care delivery system that is patient and family centered advances competencies that are essential in caring for families dealing with younger onset dementia. Most importantly is taking the time to listen to the voices of family members who are living with the changes associated with the insidious onset of dementia, and incorporating their knowledge of their family members into the plan of care.

Dementia is primarily associated with the aging population, and the syndromes associated with dementia are generally included in curricula focused on older adults. Therefore, including additional education on types of younger onset dementia may help enlighten future nurses'

understanding of the multiple forms of these rare diseases. This is particularly important in the education of advanced practice nurses who may encounter this in a family practice setting.

Nurses at all levels are expected to use evidence-based research findings in their practice; therefore, nursing curriculum must provide a strong emphasis on evidence-based nursing practice and nursing research. Benner et al. (2010, p.209) identified the need for nursing students to “develop projects in actual clinical settings that reflect both evidence based practice and exemplary nursing practice.” “To close the research-practice gap and effect improvement in patient outcomes, new approaches must be adopted that go beyond classroom education and better align nurse scientists with practicing nurses”(Duffy et al., 2015, p. 158). Faculty should encourage projects which focus on the care of individuals with younger onset dementia and their caregivers, to enhance the competencies of nurses in providing care and facilitating relationship transition in this vulnerable dyad. This approach may help bridge the gap currently identified between school and practice.

Finally, education on holistic nursing and alternative therapies may be very beneficial in helping individuals and families cope with a collection of diseases that have no curative treatments available. The behavioral symptoms associated with dementia are difficult for caregivers to manage and are often the impetus for transition to a long-term care setting. Follow-up contact with participants in this study in February 2017 revealed that three of the affected spouses had been placed in long-term care facilities since the time of the interviews, and one of the three died in January 2017, highlighting the fragility of their situations.

In summary, it is critical that students in nursing programs are educated to help families cope with the challenges of younger onset dementia in order to serve as advocates for their patients and families as they collaborate with other members of the interdisciplinary team.

Nursing Practice

“The goal of the discipline of nursing is quality of life from the person’s, family’s and community’s perspective (Parse, 1998, p. 69).” In the previous section, the focus was on the need to educate nurses at the undergraduate and advanced practice level on competencies needed to care for individuals with younger onset dementia and their caregivers. The logical next step is the application of knowledge and ability to demonstrate the competencies necessary to provide nursing care for this vulnerable dyad.

Nurses are likely to be the healthcare professionals who prepare individuals and families for impending transitions and who facilitate the process of learning new skills associated with caregiving for a partner with younger onset dementia (Meleis et al., 2000). Therefore, it is imperative that nurses understand the myriad of diseases associated with the syndrome of dementia. This knowledge must be framed in the context of age, appreciating that dementia may be part of the differential diagnoses considered in persons less than 65 years old.

Social and Public Policy

The startling number of individuals predicted to succumb to the devastating effects of AD and related dementias is a major public health concern (Alzheimer’s Association, 2017). Immediate action is required to halt the unacceptable trend with its negative impact on our communities and the health care system in the United States. The face of Alzheimer’s will

become all too familiar as the numbers grow. A commitment to a thorough, heartfelt, and innovative approach to finding results will yield significant returns on our investment, relief to those currently suffering from the disease, and peace of mind to millions of baby boomers who may otherwise get the disease (Alzheimer's Association, 2011, p. 14).

It is imperative that policies are enacted which address the major challenges we face in dealing with the Alzheimer's epidemic. The need to fund research is critical to finding strategies to prevent, treat, and ultimately find cures for this terminal disease. Early diagnosis has been identified as a critical component in adequate care planning and the provision of community support for the individual with Alzheimer's and their caregivers.

The National Alzheimer's Project Act (S.3036) was passed into law in 2011. This required the development of a national strategic plan to address the multidimensional issues caused as a result of the rising numbers of individuals afflicted with AD. The challenge is the implementation of this plan at the Federal level to address Alzheimer's research, care, institutional services, and home and community based programs. The Advisory Council on Alzheimer's Research, Care and Services is charged with this responsibility. The latest update from the Advisory Council meeting in 2013 revealed several initiatives focused on capturing, standardizing, and making freely available the massive amounts of DNA and imaging data now available through technology, and how this new information can be integrated with other clinical data (Retrieved from: <https://www.nia.nih.gov/alzheimers/features/national-alzheimers-project-act-update>).

Further action must be taken at the local, state and federal levels to meet the following goals: (1) provide better medical care and outcomes for individuals with AD and related

dementias; (2) allocate monetary and support services for the large number of unpaid family caregivers; and (3) commit to funding research to prevent, cure or slow the progression of this devastating disease. Two critical pieces of legislation: (1) The Alzheimer's Breakthrough Act of 2011 (H.R. 1897) and (2) the Health Outcomes, Planning, and Education (HOPE) for Alzheimer's Act (S. 857/H.R. 1559) were introduced but have not been passed. Support for these two pieces of legislation is critical in the war against AD.

There is a national trend in recognizing the vital role of informal family caregivers. The Caregiver Advise Record and Enable (CARE) Act has been enacted into law in 30 states; New York is one of the 30 (Coleman, 2016). "The CARE Act requires hospitals to: (1) record the name of the family caregiver in the medical record, (2) inform the family caregiver when the patient is to be discharged, and (3) provide the family caregiver with education and instruction on the medical tasks that he or she will need to perform for the patient upon return home (Coleman, 2016, p. 1)". The focus of this legislation is primarily intended to prevent readmissions and facilitate safe transitions for patients from hospital to home under the care of family members. The public acknowledgement of the important role of family caregivers provides a gateway for future legislation regarding the special needs of spousal caregivers dealing with younger onset dementia. Acknowledging the role of caregivers segues to a discussion about patient-centered care.

The concept of patient-centered care was introduced as one of the six aims of improving healthcare in America in the landmark 2001 report published by the Institute of Medicine (IOM), *Crossing the Quality Chasm*. Patient-centeredness is defined as care that includes compassion,

empathy, and responsiveness to the needs, values, and expressed preferences of the individual patient (IOM, 2001).

There are several prominent laws that are driving the mandate for patient-centered practices. The Health Information Technology for Economic and Clinical Health Act (HITECH) (2009) provided incentive payments to hospitals and physicians for adopting electronic health records. The requirements included measures to advance electronic engagement of patients throughout the healthcare system.

The Patient Protection and Affordable Care Act (2010) widely uses the term “patient-centered” and provides additional references to initiatives which incorporate: “patient satisfaction,” “patient experience of care,” “patient and family engagement,” and “shared decision-making.” The key concept is the belief that incorporating these concepts in the delivery of healthcare promotes a system that is safer, more efficient and effective, and includes consideration of the patient and family’s values.

Lastly, the Medicare Access and CHIP Reauthorization Act (2015) prompted the transition from fee-for-service to pay-for-performance. The quality domain includes measures that address clinical care, safety care coordination, patient and caregiver experience, and population health and prevention (Millenson & Berrenson, 2015). Policy and legislation is stimulating the incorporation of patient and family centered practices across the continuum of care in the U.S.

In conclusion, the allocation of dollars and resources for research and supportive services is critical to meet the needs of families coping with younger onset dementia. While the scope of the dementia epidemic has been acknowledged, the provision of actual monies has been limited.

Therefore, nurses and other healthcare providers must advocate for this vulnerable population and seek funding for programs designed with input from families and individuals with dementia.

Nursing Research

There are widespread indications for conducting further nursing research based on the findings of this study. While discovering effective treatments and ultimately a cure for Alzheimer's and related dementias, remains an underpinning in research on this topic, there is a need to learn about the unique needs of the families and individuals affected by younger onset dementia. The findings have exposed a dearth of health care providers prepared to care for these vulnerable families and a lack of services that meet their needs and expectations.

First and foremost is the need for assessing the knowledge level of all members of the interdisciplinary team about younger onset dementia. This would serve to raise the awareness level and help with the implementation of screening tools in inpatient and outpatient settings to potentially lessen the time to diagnosis. This may also lead to the development of interventions and services that meet their unique needs. It is imperative to conduct studies to broaden the understanding of what the experience means to each member of the dyad, and children when applicable. This could be accomplished through focus groups, interviews with each member of the dyad separately and then jointly, and a case study approach including all members of the family. This local knowledge is essential in the creation of services that will provide support and guidance for the family caregivers, and quality of life for the individuals with younger onset dementia.

Limitations and Recommendations

Similar to all nine studies in the initial literature review which explored the needs of individuals afflicted with younger onset dementia, this study has limited statistical significance due to the small sample size and homogeneous subject characteristics. While this study was not designed to be gender specific, all nine participants were women. All of the participants were married to their spouses in heterosexual relationships; 77% having been married 21+ years.

The homogeneity of the participants in this study is a limiting factor. Therefore, it is recommended that studies be conducted on the lived experience of significant others caring for a partner with younger onset dementia with subjects of both genders, diversity in ethnicity, religion, socio-economic status and same-sex relationships. An additional recommendation is to conduct a study which includes the spouse and the partner with younger onset dementia in order to broaden the understanding of relationship transition perceptions from both members of the dyad. Lastly, the impact on adolescent and young adult children living in the home was a significant finding in this study. A study designed to include all members of the family living in the home with the individual with younger onset dementia may enhance the understanding of the families' lived experience. As the lived experience of families dealing with younger onset dementia is better understood, research instruments can be developed for quantitative studies that may aid in the development of strategies that will help support the caregivers, other family members, and the individuals with younger onset dementia.

Personal Reflections

My experience in geriatric nursing and passion for improving the health care of older adults led me to pursue the topic of dementia. As I began the literature review and developed my

proposal, the gap in studies focused on younger onset dementia piqued my interest. I have been given the irreplaceable opportunity to learn about this phenomenon in the natural setting. With each interview, I felt privileged to be accepted as a professional but also as a confidante as the subjects described their individual experiences. I am not certain if this would have been the same if the subjects had been male. It was surprising to me, that whether the conversation flowed easily or had to be gently facilitated, the participants readily shared their innermost thoughts and feelings about their day-to-day lives. It was such a moving experience that it was impossible to stop thinking about the struggles of each and every one of the participants, as I quite literally dwelled in data. The overwhelming sense that there was finally someone who was interested in what they had to say was conveyed over and over.

The sense that they were tethered to their partners was a visual image in my mind as they communicated a sense of responsibility combined with isolation. The sense of being alone in this journey pertained to interactions with friends, family members and most disturbingly with health care providers. I am awed by the resilience of the participants in this study who have each been steadfast in their commitment to care for their spouses often in the face of significant obstacles, a lack of resources, and inadequate information about what they are dealing with and how to manage. A compelling sense of urgency was conveyed when it was discovered that three of the afflicted spouses had been placed in long-term care within six months of the interviews.

Conclusion

The health care system in the United States is ill prepared to manage the challenges posed by the needs of the growing number of families dealing with dementia. This study highlighted the unique needs of a distinct sub-group, significant others caring for partners with younger onset

dementia. The physical and psychological health and well-being of spousal caregivers is often ignored by family members, friends, and more importantly health care providers. The findings of this study provide an impetus for further research with this vulnerable dyad and their families.

References

- Allen, S. M., Goldscheider, F., & Ciambone, D. A. (1999). Gender Roles, Marital Intimacy, and Nomination of Spouse as Primary Caregiver. *The Gerontologist*, 39(2), 150-158.
- Alzheimer's Association. (2006). *Early onset dementia: a national challenge, a future crisis*. Retrieved from http://www.alz.org/national/documents/reports_early_onset_summary.pdf
- Alzheimer's Association. (2011). *Generation Alzheimer's, the defining disease of the baby boomers*. Retrieved from www.alz.org
- Alzheimer's Association. (2015b). *Changing the trajectory of Alzheimer's Disease: how a treatment by 2025 saves lives and dollars*. Retrieved from www.alz.org/trajectory
- Alzheimer's Association. (2017). *2017 Alzheimer's disease facts and figures*. Retrieved from www.alz.org
- Alzheimer's Breakthrough Act (2011), H.R. 1897. Retrieved from: www.congress.gov/bill/112th-congress/house-bill/1897
- Alzheimer's Disease International. (2015). *World Alzheimer report 2015 the global impact of dementia and analysis of prevalence incidence cost and trends*. Retrieved from www.alz.co.uk
- Arai, A., Matsumoto, T., Ikeda, M., & Arai, Y. (2007). Do family caregivers perceive more difficulty when they look after patients with early onset dementia compared to those with late onset dementia? *International Journal of Geriatric Psychiatry*, 22, 1255-1261. <http://dx.doi.org/10.1002/gps.1935>
- Ascher, E. A., Strum, V. E., Seider, B. H., Holley, S. R., Miller, B. L., & Levenson, R. W. (2010, Jan-March). Relationship satisfaction and emotional language in frontotemporal dementia

- and Alzheimer's disease patients and spousal caregivers. *Alzheimer's Disease and Associated Disorders*, 24(1), 49-55. <http://dx.doi.org/10.1097/WAD.0b013e3181bd66a3>
- Bakker, C., De Vugt, M. E., Vernooij-Dassen, M., Van Vliet, D., Verhey, F. R., & Koopmans, R. T. (2010). Needs in Early Onset Dementia: a qualitative case from the NeedYD Study. *American Journal of Alzheimer's Disease & Other Dementias*, 25, 634-640. <http://dx.doi.org/10.1177/1533317510385811>
- Bakker, C., DeVugt, M. E., VanVliet, D., Verhey, F. R., Pijenburg, Y. A., Vernooij, M. J., & Koopmans, R. T. (2013, January). The use of formal and informal care in early onset dementia: results from the NeedYD study. *American Journal of Geriatric Psychiatry*, 21(1), 37-45. <http://dx.doi.org/10.1016/j.jagp.2012.10.004>
- Bazeley, P. (2013). *Qualitative data analysis, practical strategies*. Thousand Oaks, California: Sage.
- Benner, P., Sutphen, M., Leonard, V., & Day, L. (2010). *Educating nurses, a call for radical transformation*. San Francisco, California: Josey-Bass.
- Bird, T. D. (2015). *Alzheimer Disease Overview*. Retrieved from <http://www.ncbi.nlm.nih.gov/books/1NBK1161>
- Boland, D. L., & Sims, S. L. (1996). Family care giving at home as a solitary journey. *Image: The Journal of Nursing Scholarship*, 28(1), 55-58.
- Burns, E. J., Quinn, S. J., Abernathy, A. P., & Currow, D. C. (2015, October). Caregiver expectations: predictors of a worse than expected caregiving experience at the end of life. *Journal of Pain and Symptom Management*, 50(4), 1-9. <http://dx.doi.org/10.1016/j.jpainsymman.2015.04.017>

- Chick, N., & Meleis, A. I. (1986). Transitions: a nursing concern. In *nursing research methodology* (pp. 237-257). Boulder, Colorado: Aspen Publications.
- Colaizzi, P. F. (1978). Psychological research as the phenomenologist views it. In R. S. Valle & M. King (Eds.), *Existential phenomenological alternatives for psychology*. New York: Oxford University Press.
- Coleman, E. A. (2016). Family caregivers as partners in care transitions: the Caregiver Advise Record and Enable Act. *Journal of Hospital Medicine*, 00(00), 1-3.
- Collins, J. A., Crump, S., Buckwalter, K. C., Hall, G. R., Gerdner, L. A., & Kudart, P. (1995, April). Uncovering and managing denial during the research process. *Archives of Psychiatric Nursing*, IX (2), 62-67.
- Cooper, C., Katona, C., Orrell, M., & Livingston, G. (2008, March 27). Coping strategies, anxiety and depression in caregivers of people with Alzheimer's disease. *International Journal of Geriatric Psychiatry*, 23, 929-936. <http://dx.doi.org/10.1002/gps.2007>
- Corcoran, M. A. (2011, February 18, 2011). Caregiving styles: a cognitive and behavioral typology associated with dementia family caregiving. *The Gerontologist*, 51, 463-472. <http://dx.doi.org/10.1093/geront/gnr002>
- Creswell, J. W. (2013). *Qualitative inquiry & research design: Choosing among five approaches* (Third ed.). United States of America: Sage Publications, Inc.
- Cruzado, J. A., & Elvira de la Morena, M. J. (2013). Coping and distress in caregivers of patients with disorders of consciousness. *Brain Injury*, 27, 793-798. <http://dx.doi.org/10.3109/02699052.2013.793402>

- Czaja, S. J., Gitlin, L. N., Schulz, R., Zhang, S., Burgio, L., Stevens, A. B., Gallagher-Thompson, D. (2009). Development of the risk appraisal measure: a brief screen to identify risk areas and guide interventions for dementia caregivers. *Journal of the American Geriatrics Society*, 57, 1064-1072. <http://dx.doi.org/10.1111/j.1532-5415.2009.02260.x>
- Davies, H. D., Newkirk, L. A., Pitts, C. B., Coughlin, C. A., Sridhar, S. B., Zeiss, L. M., & Zeiss, A. M. (2010,). The impact of dementia and mild memory impairment (MMI) on intimacy and sexuality in spousal relationships. *International Psychogeriatrics*, 22(4), 618-628. <http://dx.doi.org/10.1017/S1041610210000177>
- Davies, H. D., Zeiss, A.M., Shea, E. A., & Tinklenberg, J.R. (1998). Sexuality and intimacy in Alzheimer's patients and their partners. *Sexuality and Disability*, 16(3), 193-203.
- Davies, S. (2005). Meleis's theory of nursing transitions and relatives' experiences of nursing home entry. *Journal of Advanced Nursing*, 52(6), 658-671.
- Descutner, C.J., & Thelen, M.H. (1991). Development and validation of a fear-of-intimacy scale. *Psychological Assessment*, 3, 218-225.
- Ducharme, F., Kergoat, M., Antoine, P., Pasquier, F., & Coulombe, R. (2013). The unique experience of spouses in Early Onset Dementia. *American Journal of Alzheimer's Disease & Other Dementias*, 28(6), 634-641. <http://dx.doi.org/10.1177/1533317513494443>
- Ducharme, F., Lachance, L., Kergoat, M., Coulombe, R., Antoine, P., & Pasquier, F. (2015). A comparative descriptive study of characteristics of early-and late-onset dementia family

- caregivers. *American Journal of Alzheimer's Disease & Other Dementias*, 1-9.
<http://dx.doi.org/10.1177/1533317515578255>
- Ducharme, F., Levesque, L., Lachance, L., Kergoat, M., & Coulombe, R. (2011). Challenges associated with transition to caregiver role following disclosure of Alzheimer disease: A descriptive study. *International Journal of Nursing Studies*, 48, 1109-1119.
<http://dx.doi.org/10.1016/j.nurstu.2011.02.011>
- Duffy, J.R., Culp, S., Yarberry, C., Stroupe, L., Sand-Jecklin, K., & Coburn, A.S. (2015, March). Nurses' research capacity and use of evidence based practice in acute care. *The Journal of Nursing Administration*, 45(3), 158-164.
- Duggleby, W. D., Swindle, J., Peacock, S., & Ghosh, S. (2011). A mixed methods study of hope, transitions, and quality of life in family caregivers of persons with Alzheimer's disease. *BMC Geriatrics*, 11.
- Elvish, R., Lever, S., Johnstone, J., Cawley, R., & Keady, J. (2013). Psychological interventions for carers of people with dementia: a systematic review of quantitative and qualitative evidence. *Counselling and Psychotherapy Research*, 13(2), 106-125.
<http://dx.doi.org/10.1080/14733145.2012.73962>
- Erikson, E. H. (1950). *Childhood and Society*. New York, NY: W.W. Norton & Company.
- Eriksson, H., & Sandberg, J. (2008). Transitions in men's caring identities: experiences from home based care to nursing home placement. *International Journal of Older People Nursing*, 131-137.

- Farran, C. J., Miller, B. H., Kaufman, J. E., Donner, E., & Fogg, L. (1999). Finding meaning through caregiving: development of an instrument for family caregivers of persons with Alzheimer's disease. *Journal of Clinical Psychology*, 55(9), 1107-1125.
- Ford, J. L., Linde, B. D., Gigliotti, C., & Kim, K. Y. (2012). Grief experiences of 3 caregiving wives of veterans with dementia. *American Journal of Hospice & Palliative Medicine*, 30(2), 137-145. <http://dx.doi.org/10.1177/1049909112446847ajhpm.sagepub.com>
- Forsund, L. H., Skovdahl, K., Kiik, R., & Ytrehus, S. (2014). The loss of a shared lifetime: a qualitative study exploring spouses' experiences of losing couple hood with their partner with dementia living in institutional care. *Journal of Clinical Nursing*, 24, 121-130. <http://dx.doi.org/10.1111/jocn.12648>
- Gaia, A. C. (2002). Understanding emotional intimacy: a review of conceptualization, assessment and the role of gender. *International Social Science Review*, 77(3/4), 151-170.
- Galvin, K., Todres, L., & Richardson, M. (2005). The intimate mediator: A carer's experience of Alzheimer's. *Scandinavian Journal of Caring Science*, 19, 2-11.
- Ghoshal, N., & Cairns, N. J. (2013, September/October). Unravelling the mysteries of Frontotemporal Dementia. *Missouri Medicine*, 110(5), 411-416.
- Gibson, A. K., Anderson, K. A., & Acocks, S. (2014). Exploring the service and support needs of families with Early Onset Alzheimer's Disease. *American Journal of Alzheimer's Disease & Other Dementias*, 29(7), 596-600. <http://dx.doi.org/10.1177/1533317514558160>
- Grady, P. A., & Rosenbaum, L. M. (2015). The Science of Caregiver Health. *Journal of Nursing Scholarship*, 47, 197-199.

- Graham, J. M., Diebels, K. J., & Barnow, Z. B. (2011). The reliability of relationship satisfaction: a reliability generalization meta-analysis. *Journal of Family Psychology*, 25(1), 39-48. <http://dx.doi.org/10.1037/a0022441>
- Groenewald, T. (2008). Memos and memoing. In L. M. Given (Ed.), *The SAGE encyclopedia of qualitative research methods*, pp. 505-506. Los Angeles, Thousand Oaks, California: SAGE Publications.
- Gronning, H., Kristiansen, S., Dyre, D., Rahmani, A., Gyllenborg, J., & Hogh, P. (2013, July). Caregiver burden and psychosocial services in patients with early and late onset Alzheimer's disease. *Danish Medical Journal*, 60(7), 1-5.
- Guberman, N., Lavoie, J., Blein, L., & Olazabal, I. (2012, January 31). Baby boom caregivers: care in the age of individualization. *The Gerontologist*, 52(2), 210-218. <http://dx.doi.org/10.1093/geront/gnr/>
- Hain, D., Touhy, T. A., Compton Sparks, D., & Engstrom, G. (2014, June). Using narratives of individuals and couples living with early stage dementia to guide practice. *Journal of Nursing Practice Applications & Reviews of Research*, 4(2), 82-93. <http://dx.doi.org/10.13178/jnparr.2014.0402.0408>
- Harris, P. B. (2009). Intimacy sexuality and early-stage dementia the changing marital relationship. *Alzheimer's Care Today*, 10(2), 63-77.
- Health Information Technology for Economic and Clinical Health Act (HITECH) (2009). Retrieved from: hhs.gov/hipaa/for-professionals/specialty-topics/hitech-act-enforcement-interim-rule

- Health Outcomes, Planning, and Education (HOPE) for Alzheimer's Act, 2015-2016 (S. 857/ H. 1559). Retrieved from: www.congress.gov/bill/114th-congress/senate-bill/857 and www.congress.gov/congress/house-bill/1559
- Hook, M. K., Gerstein, L. H., Detterich, L., & Gridley, B. (2003, Fall). How close are we? Measuring intimacy and examining gender differences. *Journal of Counseling & Development, 81*, 462-472.
- Hughes, Langston (1990), Harlem. *Selected Poems of Langston Hughes*, Random House Inc.
- Retrieved from: <https://www.poetryfoundation.org/poems-and-poets/poems/detail/46548>
- Iavarone, A., Ziello, A. R., Pastore, F., Fasanaro, A. M., & Poderico, C. (2014). Caregiver burden and coping strategies in caregivers of patients with Alzheimer's disease. *Neuropsychiatric Disease and Treatment, 10*, 1407-1413.
- <http://dx.doi.org/10.2147/NDT.558063>
- Im, E. (2011). Transitions theory: A trajectory of theoretical development in nursing. *Nursing's Outlook, 59*, 278-285.
- Im, E., & Meleis, A. I. (1999, December). Situation-specific theories: philosophical roots, properties, and approach. *Advances in Nursing Science, 22*(2), 11-24.
- Ingersoll-Dayton, B., Spencer, B., Kwak, M., Scherrer, K., Allen, R. S., & Campbell, R. (2013). The couple's life story approach: a dyadic intervention for dementia. *Journal of Gerontological Social Work, 56*, 237-254.
- <http://dx.doi.org/10.1080/01634372.2012.758214>
- Institute of Medicine (2001). *Crossing the Quality Chasm*. Washington D.C., National Academy Press.

- Institute of Medicine (2010). *The future of nursing: leading change, advancing health*. Retrieved from <http://www.thefutureofnursing.org/IOMreport>
- Jarmolowicz, A. I., Chen, H., & Panegyres, P. K. (2015). The patterns of inheritance in early-onset dementia: Alzheimer's disease and frontotemporal dementia. *American Journal of Alzheimer's Disease & Other Dementias*, 30(3), 299-306.
<http://dx.doi.org/10.1177/1533317514545825aja.sagepub.com>
- Jones, R. W., Romeo, R., Trigg, R., Knapp, M., Sato, A., King, D.,...Lacey, L. (2015). Dependence in Alzheimer's disease and service use costs, quality of life, and caregiver burden: The DADE study. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 11(3), 280-290. <http://dx.doi.org/10.1016/j.jalz.2014.03.001>
- Judge, K. S., Yarry, S. J., Looman, W. J., & Bass, D. M. (2012, August). Improved strain and psychosocial outcomes for caregivers of individuals with dementia: findings from Project ANSWERS. *The Gerontologist*, 53(2), 280-292. <http://dx.doi.org/10.1093/geront/gns076>
- Kaiser, S., & Panegyres, P. K. (2007, January). The psychosocial impact of young onset dementia on spouses. *American Journal of Alzheimer's Disease & Other Dementias*, 21(6), 398-402. <http://dx.doi.org/10.1177/1533317506293259>
- Kang, H. S., Myung, W., Na, D. L., Kim, S. Y., Lee, J., Han, S., ... Kim, D. K. (2014). Factors associated with caregiver burden in patients with Alzheimer's disease. *Psychiatry Investigation*, 11(2), 152-159. <http://dx.doi.org/10.4306/pi.2014.11.2.152>
- Karney, B. R., & Bradbury, T.N. (1997). Neuroticism, marital interaction, and the trajectory of marital satisfaction. *Journal of Personality and Social Psychology*, 72, 1075-1092.

- Kim, H., Chang, M., Rose, K., & Kim, S. (2011). Predictors of caregiver burden in caregivers of individuals with dementia. *Journal of Advanced Nursing*, 68(4), 846-855.
<http://dx.doi.org/10.1111/j1365-2648.2011.05787.x>
- Koedam, E. L., Lauffer, V., Van der Vlies, A. E., Van der Flier, W. M., Scheltens, P., & Pijnenburg, Y. A. (2010). Early-versus late-onset Alzheimer's Disease: more than age alone. *Journal of Alzheimer's Disease*, 19, 1401-1408. <http://dx.doi.org/10.3233/JAD-2010-1337>
- Kraijo, H., De Leeuw, R., & Schrijvers, G. (2014). How spouses evaluate nursing home placement of their demented partner: a study about the end of perseverance time. *Scandinavian Journal of Caring Sciences*, 29, 101-109.
<http://dx.doi.org/10.1111/scs.12137>
- Kuppuswamy, M., Davies, H. D., Spira, A. P., Zeiss, A. M., & Tinklenberg, J. R. (2007). Sexuality and intimacy between individuals with Alzheimer's disease and their partners: caregivers describe their experiences. *Clinical Gerontologist*, 30(3), 75-81.
http://dx.doi.org/10.1300/JO18v30n03_06
- Kuruppu, D. K., & Matthews, B. R. (2013). Young-onset dementia. *Seminars in Neurology*, 33, 365-385. <http://dx.doi.org/10.1055/s-0033-1359320>
- Laske, C., Sohrabi, H. R., Frost, S. M., Lopez-de-Ipina, K., Gerrard, P., Buscema, M., ... O'Bryant, S. E. (2104). Innovative diagnostic tools for early detection of Alzheimer's disease. *Alzheimer's & Dementia*, 1-18. <http://dx.doi.org/10.1016/j.jalz.2014.06.004>
- Leggett, D. (2007). The aging workforce-helping employees navigate midlife. *AAOHN Journal*, 55(4), 169-175.

- Locke, H. J., & Wallace, K. M. (1959). Short marital adjustment and prediction tests: their reliability and validity. *Marriage and Family Living*, 21, 251-255.
- Martin, K. (2012, September). Carers and traumatic brain injury: a qualitative synthesis. *International Journal of Therapy and Rehabilitation*, 19(9), 504-513.
- Marwit, S. J., & Meuser, T. M. (2002). Development and initial validation of an inventory to assess grief in caregivers of persons with Alzheimer's disease. *The Gerontologist*, 42(6), 751-765.
- Massimo, L., Evans, L. K., & Benner, P. (2013). Caring for loved ones with frontotemporal degeneration: the lived experiences of spouses. *Geriatric Nursing*, 34, 302-306.
<http://dx.doi.org/10.1016/j.gerinurse.2013.05.001>
- Meleis, A. I., Sawyer, L., & Im, E. (2000, September). Experiencing transitions: an emerging middle-range theory. *Advances in Nursing Science*, 23(1), 12-28.
- Merleau-Ponty, M. (2014). *Phenomenology of perception*. New York, NY: Routledge. (Original work published 1945).
- Miller, R. S., & Lefcourt, H. M. (1982). The assessment of intimacy. *Journal of Personality Assessment*, 46, 514-518.
- Millenson, M. L., & Berenson, R. A. (October 2015). The Road to Making Patient-Centered Care Real: Policy Vehicles and Potholes. *Urban Institute*.
- Mittelman, M. M., & Bartels, S. J. (2013, April). Translating research into practice: case study of a community-based dementia caregiver intervention. *Health Affairs*, 33(4), 587-595.
<http://dx.doi.org/10.1377/hlthaff.2013.1334>

- Moore, K. A., McCabe, M. P., & Stockdale, J. E. (1998). Factor analysis of the Personal Assessment of Intimacy in Relationships Scale (PAIR): engagement, communication and shared friendships. *Sexual and Marital Therapy*, 13(4), 361-368.
- Moore, K., Ozanne, E., Ames, D., & Dow, B. (2013). How do family carers respond to behavioral and psychological symptoms of dementia? *International Psychogeriatrics*, 25(5), 743-753. <http://dx.doi.org/10.1017/S1041610213000070>
- Morris, L. W., Morris, R. G., & Britton, P. G. (1988). The relationship between marital intimacy, perceived strain and depression in spouse caregivers of dementia sufferers. *British Journal of Medical Psychology*, 61, 231-236.
- Morrissey, J. (2014, December). What we do (and don't) know about dementia. *Health Progress*, 7-11. Retrieved from www.chausa.org
- Narayan, S., Lewis, M., Tornatore, J., Hepburn, K., & Corcoran-Perry, S. (2001, March). Subjective responses to caregiving for a spouse with dementia. *Journal of Gerontological Nursing*, 27(3), 19-28.
- National Alzheimer's Project Act (NAPA) of 2011, Public Law 111-375). Retrieved from: aspe.hhs.gov/national-alzheimer's-project-act
- National Institutes of Health, Genetic and Rare Diseases Information Center (3/21/17). *Diseases A-Z*. Retrieved from www.rarediseasesinfo.nih.gov.
- Nogueira, M., Neto, J., Sousa, M., Santos, R., Lacerda, I., Baptista, M. & Dourado, M. (2017). Perception of change in sexual activity in Alzheimer's disease: views of people with dementia and their spouse-caregivers. *International Psychogeriatrics*. 29(2), 185-193.

- O'Callaghan, A. M., McAllister, L., & Wilson, L. (2011). Experiences of care: perspectives of carers of adults with traumatic brain injury. *International Journal of Speech-Language Pathology*, 13(3), 218-226. <http://dx.doi.org/10.3109/17549507.2011.549240>
- Olson, D. H. (1975). Intimacy and the aging family. *Realities of aging*. College of Home Economics, University of Minnesota.
- Panyavin, I., Trujillo, M.A., Peralta, S.V., Stolfi, M.E., Morelli, E., Perrin, P.B., ... Arango-Lasprilla, J.C. (2015). Examining the influence of family dynamics on quality of care by informal caregivers of patients with Alzheimer's dementia in Argentina. *American Journal of Alzheimer's Disease & Other Dementias*, 30(6), 613-621. <http://dx.doi.org/10.1177/1533317515577129>
- Parse, R. R. (1998). *The Human Becoming School of Thought, a perspective for nurses and other health professionals* (Rev. ed. of Man-living- health. c1981 ed.), Thousand Oaks, California: Sage Publications, Inc.
- Patient Protection and Affordable Care Act (PPACA) (May 2010). Public Law 111-148, 111th Congress. Retrieved from: www.hhs.gov/ppacacon.pdf.
- Perry, D. C., & Miller, B. L. (2013). Frontotemporal dementia. *Seminars in Neurology*, 33, 336-341. <http://dx.doi.org/10.1055/s-0033-1359316>
- Polit, D. F., & Beck, C. T. (2012). *Nursing research: generating and assessing evidence for nursing practice* (9th ed.). Philadelphia, Pa: Wolters Kluwer Health/Lippincott Williams & Williams.
- Portman, J. (2014). *The ethics of sex and Alzheimer's* (Fourth ed). New York: Routledge.

- Reis, H. T., & Franks, P. (1994). The role of intimacy and social support in health outcomes: Two processes or one? *Personal Relationships*, 1, 185-197.
- Robinson, L., Clare, L., & Evans, K. (2005). Making sense of dementia and adjusting to loss: psychological reactions to a diagnosis of dementia in couples. *Aging & Mental Health*, 9(4), 337-347.
- Robinson, L., Gemski, A., Abley, C., Bond, J., Keady, J., Campbell, S., ... Manthorpe, J. (2011). The transition to dementia-individual and family experiences of receiving a diagnosis: a review. *International Psychogeriatrics*, 23(7), 1026-1043.
<http://dx.doi.org/10.1017/S1041610210002437>
- Rosness, T. A., Mjorud, M., & Engedal, K. (2011, April). Quality of life and depression in carers of patients with early onset dementia, *Aging and Mental Health*, 15(3), 299-306.
- Rubin, H. J., & Rubin, I. S. (2012). *Qualitative interviewing: the art of hearing data* (Third ed.). Los Angeles, California: Sage.
- Rusbult, C. E., & Buunk, B. P. (1993). Commitment processes in close relationships: an interdependence analysis. *Journal of Social and Personal Relationships*, 10, 175-204.
<http://dx.doi.org/10.1177/026540759301000202>
- Samsi, K., Abley, C., Campbell, S., Keady, J., Manthorpe, J., Robinson, L., ... Bond, J. (2014). Negotiating a labyrinth: experiences of assessment and diagnostic journey in cognitive impairment and dementia. *International Journal of Geriatric Psychiatry*, 29, 58-67.
- Scerri, R. (2015, February/March). Living with advanced-stage Huntington's disease: an exploration of the experiences of Maltese family caregivers. *British Journal of Neuroscience Nursing*, 11(1), 20-27.

- Schaefer, M. T., & Olson, D. H. (1981, January). Assessing intimacy; the PAIR Inventory. *Journal of Marital and Family Therapy*, 7(1), 47-60.
- Shim, B., Landerman, L. R., & Davis, L. L. (2011). Correlates of care relationship mutuality among carers of people with Alzheimer's and Parkinson's disease. *Journal of Advanced Nursing*, 67(8), 1729-1738. <http://dx.doi.org/10.1111/j.1365-2648.2011.05618.x>
- Shosha, G. A. (2010). Employment of Colaizzi's strategy in descriptive phenomenology: a reflection of a researcher. *European Scientific Journal*, 8(27), 31-43. Retrieved from www.eujournal.org
- Silverberg, E. (2007). Introducing the 3-A Grief Intervention Model for dementia caregivers: acknowledge, assess and assist. *OMEGA: Journal of Death and Dying*, 54(3), 215-235.
- Silverberg, E. (2011). Applying the 3-A grief intervention approach to nursing home placement: Acknowledge, assess and assist. *Canadian Nursing Home*, 22(2), 22-25.
- Simonelli, C., Tripodi, F., Rossi, R., Fabrizi, A., Lembo, D., Cosmi, V., & Perleoni, L. (2008). The influence of caregiver burden on sexual intimacy and marital satisfaction in couples with an Alzheimer spouse. *International Journal of Clinical Practice*, 62(1), 47-52. <http://dx.doi.org/10.1111/j.1742-1241.2007.01506.x>
- Simpson, C., & Acton, G. (2013). Emotion work in family caregiving for persons with dementia. *Issues in Mental Health Nursing*, 34, 52-58. <http://dx.doi.org/10.3109/01612840.2012.720649>
- Sinclair, V. G., & Dowdy, S. W. (2005). Development and validation of the emotional intimacy scale. *Journal of Nursing Measurement*, 13(3), 193-206.

- Takano, M., & Arai, H. (2005). Gender differences and caregivers' burden in early-onset Alzheimer's disease. *Psychogeriatrics*, 5, 73-77.
- U.S. Department of Health and Human Services, Health Resources and Services Administration, Bureau of Health Workforce, National Center for Health Workforce Analysis. (December 2014). *The future of the nursing workforce: national-and state-level projections, 2012-2025*. Retrieved from <http://bhw.hrsa.gov/healthworkforce/index.html>
- Van Manen, M. (1997). *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy*. Albany, NY: SUNY Press.
- Van Manen, M. (2014). *Phenomenology of Practice*. Walnut Creek California: Left Coast Press Inc.
- Van Mierlo, L. D., Meiland, F.J.M., Van der Roest, H. G., & Droes, R. (2012). Personalised caregiver support: effectiveness of psychosocial interventions in subgroups of caregivers of people with dementia. *International Journal of Geriatric Psychiatry*, 27, 1-14.
- Van Vliet, D., Bakker, C., Koopmans, R. T., Vernooij-Dassen, M. J., Verhey, F. R., & De Vugt, M. E. (2010). Research protocol of the NeedYD-study (Needs in Young onset Dementia): a prospective cohort study on the needs and course of early onset dementia. *BMC Geriatrics*, 10:13.
- Van Vliet, D., De Vugt, M. E., Bakker, C., Koopmans, R. T., & Verhey, F. R. (2010). Impact of early onset dementia on caregivers: a review. *International Journal of Geriatric Psychiatry*, 25, 1091-1100.

- Wadsworth, L. L., & Facer, R. L. (2016). Work-family balance and alternative work schedules: exploring the impact of 4-day workweeks on state employees. *Public Personnel Management, 45*(4), 382-404.
- Waring, F. M., & Reddon, J. R. (1983). The measurement of intimacy in marriage. *Journal of Clinical Psychology, 39*, 53-57.
- Warren, J. D., Rohrer, J. D., & Rossor, M. N. (2013, August 6). Frontotemporal dementia. *BMJ*. <http://dx.doi.org/10.1136/bmj.f4827>
- Werner, P., Stein-Shvachman, I., & Korczyn, A. D. (2009, May 27). Early onset dementia: clinical and social aspects. *International Psychogeriatrics, 21*, 631-636. <http://dx.doi.org/10.1017/S1041610209009223>
- Whitebird, R. R., Kreitzer, M., Crain, A. L., Lewis, B. A., Hanson, L. R., & Enstad, C. J. (2012). Mindfulness-based stress reduction for family caregivers: a randomized control trial. *The Gerontologist, 53*(4), 676-686. <http://dx.doi.org/10.1093/geront/gns126>
- Wilkinson, L., & the Task Force on Statistical Inference, &. (1999). Statistical methods in psychology journals: guidelines and explanations. *American Psychologist, 54*, 594-604.
- Williams, C. (2011, June). Marriage and mental health: When a spouse has Alzheimer's disease. *Archives of Psychiatric Nursing, 25*(3), 220-222. <http://dx.doi.org/10.1016/j.apnu.2011.02.003>
- Wright, J. (2005). Coaching mid-life, baby boomer women in the workplace. *Work, 179*-183.
- Yoo, H., Bartle-Haring, S., Day, R. D., & Gangamma, R. (2014). Couple communication, emotional and sexual intimacy, and relationship satisfaction. *Journal of Sex & Marital Therapy, 40*(4), 275-293. <http://dx.doi.org/10.1080/0092623X.2012.751072>

- Zarit, S. H., Kim, K., Femia, E. E., Almeida, D. M., & Klein, L. C. (2013). The effects of adult services on family caregivers' daily stress, affect, and health: outcomes from the Daily Stress and Health (DaSH) Study. *The Gerontologist*, 54(4), 570-579.
<http://dx.doi.org/10.1093/geront/gnt045>
- Zhang, X., Yeung, D. Y., Fung, H. H., & Lang, F. R. (2011). Changes in peripheral social partners and loneliness over time: the moderating role of interdependence. *Psychology and Aging*, 26(4), 823-829. <http://dx.doi.org/10.1037/a0023674>



Appendix A: Study Announcement

Would you like to share your story about caring for a partner with younger onset dementia?

In my work as a registered nurse, I have met many families caring for a loved one with dementia. I am conducting a nursing research study to gain a deeper understanding of how significant others experience day-to-day living with a partner with younger onset dementia.

Are you:

- Currently living with someone as a close couple, in a committed relationship such as with a significant other, spouse, partner, girlfriend/boyfriend who was diagnosed with dementia before age 65?
- Interested in sharing your thoughts and feelings about living with a partner with younger onset dementia?

If you answered yes to both questions, you are invited to participate in a nursing research study being conducted by Diane Peyser RN, a registered nurse and student in the PhD in Nursing Program at Molloy College in Rockville Centre, NY.

- If you agree to participate, you will be asked to meet for one to two hours to share your experience as a significant other living with a partner with younger onset dementia. Your identity will be kept confidential.

The purpose of this study is to explore the unique experience of being a care partner for a significant other with younger onset dementia. This information may help health care professionals develop strategies to support individuals during this time. If you are interested in participating in this study or have any questions, please contact:

Diane Peyser: 347-899-6739 or email: dpeyser@lions.molloy.edu.

Appendix B: Informed Consent

TITLE: The Lived Experience of Relationship Transition in Significant Others Caring for a Partner with Younger Onset Dementia

INVESTIGATOR: Diane J Peyser, M.S., R.N., PhD(c)

I am a registered nurse and a doctoral student at Molloy College interested in studying the experience of significant others living with a partner with younger onset dementia.

Committee Chairperson: Dr. Margaret Whelan, EdD, APRN, FNP-BC

You are being asked to participate in a research study to answer specific questions.

This consent form will explain:

- The purpose of the study
- What you will be asked to do
- The potential risks and benefits of participating in this research study

You should ask questions before you agree to participate in this research study. You can also ask questions any time during the study.

Purpose of this Research Study:

The purpose of this study is to learn how significant others experience changes in their relationship living with a partner diagnosed with dementia younger than age 65.

Expected Duration of the Study:

This research study will take place over an approximately 6 months, during which time approximately 15 participants will be interviewed.

Study Procedures:

If you agree to be in this study, you will discuss questions about your relationship with your significant other and your experiences dealing with younger onset dementia. You will be asked to complete a Demographic Form that may take 5-10 minutes. You will be asked to participate in 1-2 interviews lasting approximately 1-2 hours each. You will choose the time and place that is convenient for you to participate in these interviews. A list of questions will be used to guide the interview(s). You may review these questions prior to the start of the interview(s). You will be asked to share only what you want to share about your experiences. The interview(s) will be audio-taped using a digital voice recorder and later transcribed to written form by a professional transcription service. Your confidentiality will be maintained by only using pseudo-names (not your real name), selected by you, that will be used in all documents. You may be asked to verify a final description the ideas that are identified after data analysis has concluded to determine if you feel these are accurate. There may be a subsequent interview of approximately 30-60 minutes in-

person, by telephone or email for your convenience. There is no right or wrong answers. All of your responses will be kept confidential.

Possible Benefits to Participants or to Others: There are no direct benefits from participating in this study. It is possible you may feel better in talking about your experiences and knowing that you are adding to knowledge that may help others.

Reasonably Possible Risks or Discomforts: There are no direct anticipated risks to participating in this study. You will be asked to share some personal information. You may feel strong emotions when talking about some of the topics. It is possible that recalling past experiences as well as current circumstances may be potentially upsetting. If it becomes uncomfortable for you to go through the experience, you will be able to stop the interview at any time or discontinue participating in the study. You may also choose to have any of your data deleted at any time. A list of community resources can also be provided to you if desired.

Cost/compensation:

There is no cost to you for taking part in this study. You will be provided with a \$15 gift card after completing your participation.

Confidentiality:

Your interview information will be kept confidential. Your name will not be used during the interview or the audio-recording. You will be identified by a study number and a pseudo-name that you select. All data will be kept securely locked by the investigator and only those people who are involved in the research (faculty dissertation committee and transcriber) will be able to review data. None of your personal identifying information such as name, family names, address, or place of employment will be used. No personal identifying data will be used in any final written document or publication.

Voluntary Participation:

Your participation in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time during the study without penalty.

Contacts for questions about this research study:

If you have questions at any time about this research or want to discuss any possible study-related concerns, please contact the investigator:

Diane J Peyser, MS, RN at dpeyser@lions.molloy.edu or call: 347-899-6739.

Or

Dr. Margaret Whelan, EdD, APRN, FNP-BC at mwhelan@molloy.edu or 516-323-4000.

Professor, Barbara H. Hagan School of Nursing, Molloy College

1000 Hempstead Avenue
Rockville Centre, NY 11570

If you have questions about your rights as a research subject or if you have questions, concerns or complaints about the research, you may contact:

Molloy College Institutional Review Board
1000 Hempstead Avenue
Rockville Centre, New York 11570

Co-chairpersons: Dr. Kathleen Maurer Smith – ksmith@molloy.edu- 516-323-3801

Dr. Patricia Eckardt - peckardt@molloy.edu-516-323-3711

Consent

An explanation of the procedures to be employed in this study, in which I have voluntarily agreed to participate, has been offered to me. All my questions about the study and my participation in it have been answered to my satisfaction. I understand that the information collected will be held in confidence, and that my name will not in any way be identified. I understand that additional information about the study results will be provided at its conclusion, upon my request. I know that I am free to withdraw from this study without penalty at any time. I have read this page and the preceding two pages of this consent form. In addition, the researcher has explained the procedures in this study and the potential risks.

Subject Name (Printed)

Signature of Subject

Date

Printed Name of Person Conducting Informed Consent Discussion

Signature of Person Conducting Informed Consent Discussion

Date

Complete the following if you wish to receive a copy of the results of this study:

NAME: _____
(Typed or Printed)

ADDRESS: _____
(Street)

(City)

(State)

(Zip)

E-mail (optional) _____

Appendix C: Demographic Form

Please complete the following information about you.
All information will be kept confidential.

Subject # _____ Pseudonym _____

Interview Date _____ Time _____ Place _____

Age: _____

Gender: Male _____ Female _____

Ethnicity/Race:

White _____ Black/ African American _____ Asian _____ Hispanic origin _____ Other _____

Occupation: _____

Employment:

Working _____

Unemployed _____

Retired _____

On disability _____

Highest educational level: High School _____ Bachelor's Degree _____ Master's Degree/higher _____

Number of years married _____ or Number of years in this relationship _____

Do you attend any community or religious activities? :

(If yes, please describe) _____

Caring responsibilities (check all that apply):

Personal hygiene such as bathing _____

Handling finances _____

Managing medical care _____

Household chores _____

Number of persons living in your home: _____

Indicate who they are (relatives, friends): _____

Number of children: Mutual _____ Yours _____ Stepchildren _____

Close friendships: Yes _____ No _____

Family or friends share caring responsibilities – Yes _____ No _____

If yes, what relationship _____

Does your spouse attend an Adult Day Care program? Yes _____ No _____

Support group participation: Yes _____ No _____ Type _____

Do you use any other respite care practices? : Yes____ No__

If yes please describe_____

How would you describe your financial status? :

Secure and worry-free_____

Occasional concerns over meeting needs_____

Serious financial concerns_____

Please complete the following information about your significant other.

Age: _____

Gender: Male____ Female____

Ethnicity/Race:

White____ Black/ African American____ Asian____ Hispanic origin____ Other____

Occupation: _____

Employment:

Working_____

Unemployed_____

Retired_____

On disability_____

Highest educational level- High School____ Bachelor's Degree____ Master's Degree/higher____

Diagnosis and Type of Dementia (if known) _____

Year diagnosed_____

Year when dementia symptoms were first noticed_____

Other medical conditions such as:

Diabetes_____

Heart conditions_____

Obesity_____

Asthma_____

Other_____

Appendix D: Interview Guide

Tell me about your relationship (history as a couple) before your significant other was diagnosed with younger onset dementia. Please share what you are comfortable sharing about intimacy, communication and other important aspects of your relationship.

Tell me about the experience of living with a significant other with younger onset dementia. Please share what you are comfortable sharing about intimacy, communication and other important aspects of your relationship.

Tell me how dealing with dementia has affected your relationship with other family members, friends, job, or outside activities.

How do you feel about yourself now?

Do you feel differently about yourself since you have been living with a significant other with younger onset dementia?

Can you describe the changes that have affected your relationship with your significant other?

Tell me what you would say to someone whose significant other has just been diagnosed with younger onset dementia.

What advice would you give to someone whose significant other has just been diagnosed with younger onset dementia?

What are the most important things health care professionals need to know about living with a significant other with younger onset dementia?

Is there anything else you would like to tell me?

Appendix E: Transcriptionist Confidentiality Form

This document is to verify that each transcriptionist hired for this study will agree to confidentiality prior to and throughout the transcription process.

I am aware that the information contained in each study interview transcript belongs to the primary investigator of this study, Diane J. Peyser MS, RN, PhD(c) and that privacy and confidentiality will be maintained by me during and after my work in transcribing these interviews.

Researcher Signature _____

Transcriptionist Signature _____

Transcriptionist (Print Name) _____

Date _____