

4-20-2017

# Heart and Soul: A Phenomenology of Dementia Spouse Caregivers' Relationship Closeness

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# Heart and Soul: A Phenomenology of Dementia Spouse Caregivers' Relationship Closeness

Elena Schjaveland, PhD

University of Connecticut, 2017

All persons with dementia exhibit combinations of cognitive impairment (memory loss and aphasia), functional losses (changes in activities of daily living), and neuropsychiatric disease manifestations (fluctuating moods, behaviors and psychoses). The spouse caregiver role and life are affected by these symptoms which can cause intimacy, reciprocity, and communication issues, and frequently result in the caregiver's feelings of inadequacy, hopelessness, and embarrassment. Yet caregivers somehow manage to reconstruct and maintain a closeness as a couple.

Relationship closeness (RC) found in all marriages is simply depicted as the quality of the communal and emotional bond between husband and wife. Limited research demonstrates some elements of RC are altered by the progression of dementia disease and links RC with the couple's morbidity (ill health and depression) and caregiving outcomes (burden, coping, transcendence and efficacy). But RC is poorly defined in published studies, and not adequately or critically examined in context with dementia's cognitive impairment and neuropsychiatric symptoms, whose very characteristics disrupt critical elements of interpersonal relationships.

The purpose of this descriptive phenomenological study was to investigate the phenomenon of spouse caregiver RC; it focused on dementia and the sequelae of dementia symptoms and behaviors. The research questions were: 1) what is the fundamental structure of this phenomenon, and 2) what is the meaning of the experience of this phenomenon. This inquiry uncovered a rich description of marital RC in couples, by focusing on their memories and lived-

world experiences as caring partners, and as their spouse expressed dementia symptoms daily. Both theoretical underpinnings and qualitative research design used Colaizzi's existential philosophy and Phenomenological Reflection method of data analysis. Data emerged from the author's Individual Phenomenological Reflection and sixteen dialogal interviews. Findings revealed the meaning of the fundamental structure of RC in the face of dementia as a *journey*. Five essential constituents emerged: A past together, the present in which spouses see, feel and respond to the dementia, and lastly, a future together. The meaning expressed by spouses was woven in a tapestry of dementia symptomatology, and dyadic internal and external changes in RC described with important sub-themes such as loss and hurt, imperfect caregiving and compassionate love.

Heart and Soul: A Phenomenology of  
Dementia Spouse Caregivers' Relationship Closeness

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Submitted in Partial Fulfillment of the

Requirements for the Degree of

Doctor of Philosophy

at the

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2017

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2017

APPROVAL PAGE

Doctor of Philosophy Dissertation

Heart and Soul: A Phenomenology of  
Dementia Spouse Caregivers' Relationship Closeness

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2017

## DEDICATION

This work is dedicated to the dementia community. Although your loved ones are the clinically diagnosed patients, dementia is truly a family disease. I offer a heartfelt thank you to the many families and caregivers who have trusted me, taught me, and shared with me: their honesty and innermost feelings, the daily trials and tribulations, some joys and sorrows, and a never-ending fortitude and compassionate love.

You have my earnest admiration and respect for your daily work and effort to meet the challenges of such a heartless disease. You always seem to be there in the moment, and have the will, humor and acceptance to rise above it. God bless you. You are remembered...

### *Remembered Song*

*If time should come and steal my memories,  
If you look in my eyes and cannot see,  
If something takes away my yesterdays,  
Play these my songs and know you're hearing me.*

*And if by chance I hear the melodies,  
The faithful sun may now and then break through,  
And I will feel the warmth that used to be,  
And in remembered song, remember you.*

— *Phil Ellsworth*

## ACKNOWLEDGEMENT

A sincere thanks to an expert doctoral and research committee: Dr. Richard Fortinsky, Dr. Tom Van Hoof, Dr. Juliette Shellman, Dr. Cheryl Beck and Dr. Barbara Jacobs. My genuine gratitude goes to the professional faculties of the University of Connecticut School of Nursing, the NEAG School of Education, and the Gerontology Division of the Human Development and Family Studies Department College of Liberal Arts and Sciences.

To my nursing colleagues, medical practice affiliates and business partners, thank you for collectively instilling Toltec wisdom in me: *say what you mean, always do your best, don't make assumptions, and don't take anything personally*. To my friends, schoolmates, teachers and colleagues who shared in this journey... thank you for the countless hours of listening, voicing astute questions, providing encouragement and offering a deep understanding of what doctoral study is, and what it is not.

I have been blessed with a life full of loving and exceptional family members: my parents— Margaret and Roy, and the role models of two extraordinary aunts— Teresa and Mother Mary Edith, S.H.C.J. They instilled in me their moral compass, perseverance, kindness and wit. Thanks also to my cousins: Nancy, Marianne, Liz and Sue, who always asked about my dementia practice and academic work. Lastly, it would be impossible for me to complete this Ph.D. program without the unconditional love, understanding and support by my wonderful family: the very best sister and friend, Marcia; the adult kids of the family, Nicole and Doug; and finally, my little cupcakes: Ella and Jack ...who, when asked, “What does Nan do?” they proudly say, “*Nanny is a nurse.*”



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## Heart and Soul: A Phenomenology of Dementia Spouse Caregivers' Relationship Closeness

*Yeah, yeah, but I love him. I try very hard to find the positive. It's not always easy, right?*

*But it's, kind of, pitiful to see how this [dementia] disease diminished him.*

*You know, a very competent and capable person, now confused...and like a child...  
confused...just mildly impaired with his memory, you know...short-term memory.*

*You ask him about his time in the service, his time as a child, then he's got it all.*

*But you ask him, what day of the week it is, and it's not there;*

*how old he is, he says he is 35. ———His world stopped. Participant 004a*

### **Chapter One: Introduction to Dementia Spouse Caregiving**

The purpose of this descriptive qualitative research study was to investigate the phenomenon of spouse caregiver relationship closeness emphasizing the advent of dementia disease into the couple's life as well as the sequelae of dementia's symptoms and behaviors. Dementia caregiver spouses that the author met through a dementia clinical practice and role as a Connecticut Alzheimer's Association bureau speaker prompted the investigation. Families of persons with dementia described a gap in our U.S. care model, in that primary care and specialty providers rarely delved deeply into how the caregiver's health, their spousal roles, and their relationship with their husband or wife was secondarily affected by Alzheimer's disease and associated dementias. They specifically identified the significance of dementia's unrelenting cognitive losses and psychiatric symptoms that played a powerful impact on day to day life. The spouse caregivers were confounded by the limited understanding and empathy displayed by health care personnel, family, and friends who seemed reluctant, unknowing or unable to relate

to the caregiver's tumultuous life, and the dementia client's meta-losses and psychiatric symptoms that produced the incapacity to be an active contributing member of the marital dyad. This investigation was concerned with that experience of relationship closeness, framing couplehood when dementia became present. This study uncovered the lives and experiences of some of those dementia caregiver spouses.

The aims of Chapter One are to introduce the readers to spouse dementia caregivers, present the pivotal Auguste and Karl Deter Alzheimer story from a couple's perspective, and illustrate the foundations of dementia caregiving knowledge. This chapter reviews the study's basic terminology, generic caregiving epidemiology, and common dyadic concepts. It provides a review of this study's critical importance in the present-day diagnosis, care and empathetic treatment of dementia couples and, in the nature of qualitative research, explains the reasoning for this study's phenomenological approach.

### **The First Dementia Spouse Caregiver Story**

In developing this dissertation vis-à-vis dementia caregiving and marriage, it was necessary for the author, to look back at the anthropological history of the early Alzheimer cases of married couples. Providentially, the first documented dementia couple was found to be the first salient clinical Alzheimer's case. "August D." is famous of her own accord, but the story of her husband's role can be regarded as a conduit, a flashpoint, if you will, to the author's present day research study. The Deters' actual medical case thus launched a platform to understand, appreciate and value the spouse's protagonist role in dementia care.

This seminal Alzheimer story began in Frankfurt, Germany in November 1901 when Karl Deter brought his wife, Auguste, to the Städtische Heilanstalt für Irre und Epileptische (City Hospital for the Mentally Ill and Epileptics). There she was evaluated by Dr. Alois Alzheimer, a

psychiatrist, and neuropathologist. He meticulously documented her story and symptoms, the disease progression, her death in 1906, and finally, the historic pathologic findings of protein plaques and neuritic tangles. Dr. Alzheimer refers to Auguste Deter as Case #1 (Alzheimer, 1907, 1911).

Few scholars describe the background story of Auguste Deter as eloquently and as richly as Maurer and Maurer (2003), Page and Fletcher (2006) and Whitehouse, Maurer & Ballenger (1999). Those authors illustrated Mr. and Mrs. Deter's narrative with documents, pictures, and historical, anthropological and social theory perspectives. They chronicled the following biography.

Auguste attended school as a child and at the age of fourteen was a seamstress and was probably "in the service" of a family in Cassel, Germany. She was twenty-three in 1870 when she married Karl, moved south to Frankfurt, and had one daughter, Thekla. As the 19<sup>th</sup> century was ending, Auguste was a typical housewife in Imperial Germany. Karl was a white-collar office worker for the railway system. He clerked in the first-class ticket department. He was salaried and received a type of health care compensation, that would be today's equivalent of worker's and family health insurance coverage (Maurer & Maurer, 2003).

During the late 1800's, fundamental Prussian virtues of 'nuchternheit' and 'pflichterfullung' defined the social life in which the Deters lived. Nuchternheit refers to a simple, sober and Spartan lifestyle. Pflichterfullung represents self-discipline and hard work, decency, honesty, and a commitment to vows and readiness to serve or to do one's duty (MacDonogh, 1995). It was a rigid system of social order and classes, demanding a virtuous and moral stereotypical behavior in all tiers of German society. It is in this social model that Karl and Auguste would have lived, and they would have been measured by the neighborhood as well



(Page & Fletcher, 2006). Dementia's functional losses and psychiatric symptomatology would be at odds with expected German societal decorum, likely provoking enormous stress between the couple, the family and their social and working community. This social model is the likely reason Mr. Deter initially tried to care for Auguste himself, then sought further medical evaluations in a tiered system of health care, and later, why Karl remained dedicated to Auguste despite her declining health. Karl must have felt anguish, and at the same time, conflict as his spouse's dementia disease revealed itself— its psychotic symptoms so contrary and opposite to every virtue expected of the empire and their religion. He must have struggled with the expectation of living German values, and at the same time, searching for ways and means to conform to its social rules.

Marriage was the only respected and honorable career for women during the Victorian era, and 'kinder, kirche, kuche' or, children, church, and kitchen, dominated the German feminine role (Page & Fletcher; 2006). Conscious that this was a male dominated society, it is only from Karl's perspective (Auguste was too impaired), that he described a full and happy married life together with Auguste and Thekla; he and Auguste were, in his words, *harmonious*. He described her as somewhat excitable and having a nervous disposition, but overall rather amicable. In time, however, she no longer conformed to the social identities expected, that of being hard working, tidy and obedient to her husband. Typically, families of the time were secretive with disease and mental illness; and the Deter family could have maintained a façade of well-hidden subtle cognitive changes and mild behavior impairment consistent with mild dementia. Suddenly, Auguste and Karl were in crisis in November of 1901. There is no record of medical involvement, or Karl seeking help for Auguste's prodromal symptoms prior to this first

account (Page & Fletcher, 2006). In 21<sup>st</sup> century parlance, and translated from German, Karl related this chief complaint and review of symptoms to their local doctor.

Auguste was 51 when symptoms began. In March 1901, she suddenly expressed suspicion towards Karl related to seeing him walking down the street with a female neighbor. Expressing jealousy, she accused Karl of infidelity. From that moment on, Auguste became aloof from both her husband and the neighbor. She rebuffed physical touch. She suffered from memory loss and lost significant weight. She would pace in the apartment for no reason. Over the next months, Auguste neglected her housework, hid household objects, became incapable of handling any household money, and she made cooking blunders. It was described that she *threw the house into disorder*. She became paranoid that a local wagon driver would harm her, and assumed all the neighbors were talking about her. Auguste frequently spoke of death. Her behavioral symptoms increased; she would disrupt her fellow community, ring the neighbor's front door bells without reason, knock on, and slam doors. Auguste had late afternoon confusion, probably a sundowning syndrome, and would sometimes wake up in the night and scream for hours. Karl was so overwhelmed, he could no longer cope or care for her, and she could no longer care for the home and family. In November 1901, Mr. Deter took Auguste to their community health clinic. He received this prescription from their family doctor. It was a letter of admittance, much like a 21<sup>st</sup>-century physician emergency certificate for psychiatric commitment.

Mrs. Auguste D., . . . has been suffering for a long time from weakening of memory, persecution mania, sleeplessness, restlessness. She is unable to perform any physical or mental work. Her condition (chronic brain paresis) needs

treatment from the local mental institution (as cited in Maurer & Maurer, 2003, p. 19).

Karl was advised to take her, or likely commit her, to the Frankfurt psychiatric hospital—its local nickname Irrenschloss, translated as the “castle for insane on the hill” (Maurer & Maurer, 2003). On November 26, 1901, Dr. Alois Alzheimer hand wrote a report.

ALZHEIMER’S NOTE: She sits on the bed with a helpless expression.

Alzheimer: *What is your name?*

Auguste D.: *Auguste.*

Alzheimer: *What is your husband’s name?*

Auguste D.: *Auguste.*

Alzheimer: *Your husband?*

Auguste D.: *Ah, my husband.* [She looks as if she didn’t understand the question.]

Alzheimer: *Are you married?*

Auguste D.: *To Auguste.*

Alzheimer: *Mrs. D?*

Auguste D.: *Yes, yes, Auguste D.*

Alzheimer: *How long have you been here?* [She seems to be trying to remember.]

Auguste D.: *Three weeks.*

Alzheimer: *What is this?* [I show her a pencil.]

ALZHEIMER’S NOTE: A pen. A purse, key, diary and cigar are named correctly.

At lunch, she eats cauliflower and pork. Asked what she is eating she answers “*spinach.*”

When she was chewing meat, and asked what she was doing, she answered “*potatoes*” and “*horseradish.*” When objects are shown to her, she does not remember after a short time which objects have been shown. In between she always speaks about “*twins.*” When she is asked to write, she holds the book in such a way that one has the impression that she has a reduction in the right visual field.

Asked to write “Mrs. Auguste D.,” she tries to write “Mrs.” and forgets the rest.

It is necessary to repeat every word. Amnestic writing disorder (“Amnestische Schriftstörung”). In the evening her spontaneous speech is full of paraphasic derailments and perseverations (as cited in Whitehouse et al., 2000, pp. 13-14).

Over the next five years, Auguste D. continued to be hospitalized, becoming gradually worse with apathy, aphasia, and psychoses. She expressed mood swings; she was quiet and comforting to other patients at times, then could become depressed with inconsolable crying, or be loud and histrionic.

In 1904, Karl suffered financial problems and found it difficult to pay his contribution of 2 marks per day towards his wife’s 3<sup>rd</sup> class hospital fees. As recommended by the hospital’s administrative and financial overseers, the Social Welfare Office requested her transfer to a different, cheaper hospital in Weilmuenster. There, the local social welfare office had more influence and control of funding; she would be considered indigent, and as such, she would be cared for at the public’s expense. But it was Dr. Alzheimer who personally intervened to keep

Auguste under the treatment of the Frankfurt City Hospital for the Mentally Ill and Epileptics. He had an agenda of scholarship and wanted her to remain to document her rare disease and progress. He also developed an early bond with Auguste because they shared the same hometown of Cassel (Maurer & Maurer, 2003).

In that Frankfurt hospital, Alois Alzheimer's research was finding ground between empirical neurologic medical research, psychiatry and curative therapy. He surmised Mrs. Deter's condition was a new '*peculiar*' disease. His classmates were neurologists and neuroanatomists, Freudian and gestalt psychoanalysts, and perceptual, behavioral and existential psychologists. Each discipline expanding their scholarship daily, with a drive to learn, and thirsty to become published and famous. German physicians dominated psychiatric and neuropathologic medicine in the first half of the twentieth century. Dr. Alzheimer and his contemporary colleagues, Doctors Binswanger, Cotard, Creutzfeldt, Jakob, Lewy, and Pick, were attempting to prove psychiatric illness and symptoms could be attributed to pathological processes in the tissue of the brain; they used empirical methods, modern tissue staining procedures, and neuropathologic laboratory data. Their data, written entirely in German, was quickly translated and adapted in English (Bolla & Barba, 2005).

Karl Deter could have easily and legally, divorced Auguste, thus eliminating his financial support requirements; but he did not (Page & Fletcher, 2006). He continued to struggle with fees and medical costs. It is recorded that Mr. Deter was a devoted husband and frequent visitor to the hospital. Clearly, he had an affection and devotion towards his wife much in line with Prussian morals which valued vows and duty. But it must have been heartbreaking to see and hear a spouse so bereft and with little memory and awareness of her past, let alone their past life

together as a married couple. In an early interview with Alzheimer, Auguste was asked to write her own name and could not recall it, she lamented:

*I have, so to speak, lost myself* (as cited in Maurer & Maurer, 2003, p. 8).

Auguste's severe stage found her immobile, aphasic and with a terminal prognosis.

. . . completely stupefied, always lying in bed with legs drawn up. Regularly soiled with urine and faeces: never says anything, mutters to herself, has to be fed (as cited in Maurer & Maurer, 2003, p. 154).

Mrs. Auguste Deter died on April 8, 1906, from sepsis due to sacral and trochanter decubitus ulcers and with complications of renal failure and comorbid pneumonia (Maurer & Maurer, 2003). Subsequently, Dr. Alzheimer was permitted to perform pathologic tests on her brain using special staining techniques; he reported these findings as a peculiar disease, first in a lecture, then scholarly journals (Alzheimer, 1906, 1907, 1911). Auguste Deter's blue covered, softbound notebook—our electronic health record equivalent, and Dr. Alzheimer's original handwritten case notes were missing for almost a century until it was discovered by Dr. Konrad Maurer in the archives of the Goethe University Hospital in Frankfurt (BBC News, 2016a).

Auguste Deter's narrative is interesting for its historical significance, but more than that, one hundred years later, it still typifies the modern-day struggle confronted by spouses who find their partner in the throes of cognitive impairment with neuropsychiatric symptomatology. Auguste's poor communication due to speech and language deficiencies, memory loss—forgetfulness of her husband's name, agnosia— not recognizing a spouse, and severe paranoid delusions and confusion are at odds with the very concepts of marriage and couplehood. It would suggest Mr. Deter was overwhelmed with the disease, powerless to make his wife well, and unable to provide a return to a normal semblance of a married couple in their unique societal

cohort. He was challenged by social expectations, financial ramifications, and a medicalized health care system, which each uniquely impacted his, and Auguste's, dementia experience.

This historical saga permits the readers a historical observation of dementia dyad care. Over one-hundred years ago, overt symptoms of a medical disease, expressed as cognitive impairment and neuropsychiatric symptoms, and the newly named "Alzheimer's disease," interfered with fundamental social and couple relationships— especially marriage, personhood, dignity and social expectations. The Deters' medical record and the recount of the experience Karl Deter lived, be it very incomplete, laid the landscape for the present researcher's investigation; and as the readers will find, the dementia story is much unchanged since the early 1900's.

### **Study Terminology**

For this study, the married dementia spouse providing partnership, care, supervision, hands-on assistance, and other help to their partner with dementia is referred to as the "caregiver" and the husband or wife diagnosed with dementia is called the spouse "care-recipient" or the "individual, person, husband, or wife with dementia."

For this phenomenological analysis, relationship closeness (RC) is simply depicted as the quality of the communal and emotional bond between husband and wife. However, it is the spouse caregivers who gave voice to their perception and their description of relationship closeness.

Cognitive impairment (CI) is defined as a complex syndrome of mixed losses including any and all: 1) memory dysfunction within domains of short and long-term timeframes, memory loss causing procedural disabilities like failing to complete the steps to use equipment, and semantic process impairment causing an inability for a person's memory to retrieve words and

concepts we've acquired during a lifetime; 2) speech and conversation problems producing expressive aphasia, e.g.: anomia, less sophisticated lexicon, dysfluency, poor syntax and grammar, egocentric or one-sided speech, reduced content- often referred to as poverty of word and thought, talking and not coming to the point, and endless talking called logorrhea which is often impulsive and without social boundaries; and receptive aphasia, i.e.: lack of word and context comprehension; 3) executive problem-solving impairments; and 4) intellectual losses that disrupt recognition of people and things, and hinder a successful voluntary and purposeful motor action.

Neuropsychiatric symptoms (NPS) feature an altered level of consciousness, and a diversity of high-energy - positive and low-energy - negative mood changes, delusions, and hallucinations. In this study, cognitive impairment and neuropsychiatric symptoms (CI-NPS) are also referred to broadly as "dementia symptomatology." Cognitive impairment and neuropsychiatric symptoms subsume current literature taxonomy of behaviors and psychological symptoms of dementia, and common dementia behaviors such as wandering, sundowning, shadowing, and appetite, sleep, and incontinence maladies.

Dementia is a generic term in discussing a syndrome of progressive cognitive impairment diseases which advance slowly and in a downward trajectory in disability and functionality. Dementia symptoms of the neural pathway degeneration, cerebral lobe changes and consequential affective losses in personal expression result in cognitive, behavioral and functional impairment. Dementia is typically recognized when acquired cognitive impairment becomes severe enough to compromise occupational, social and self-care activities. These functional losses, at a minimum, require coaching from others to remember medications and



appointments, and, as they progress, sever the ability to drive and execute other motor functional skills, and eventually result in total loss of self-feeding abilities and self-contenance behaviors.

The diagnosis of Alzheimer's disease, the most common type of dementia, is characterized by impaired memory, executive dysfunction, and speech/conversational loss. Conative changes (purposeful actions which allow high, or *meta*-thinking to drive motivation and to strive to accomplish self-identified goals) also emerge during the sequential timeline of dementia diseases (Hugo & Ganguli, 2014; Smith, Gerdner, Hall & Buckwalter, 2004).

Together, the dementia caregiver and the dementia care-recipient face a terminal disease challenged by a burden of escalating care hours, physical and emotional exhaustion, and limited treatment and pharmacologic management. Dementia caregiving is demanding and overwhelming throughout a rocky continuum averaging ten years (Todd, Barr, Roberts, & Passmore, 2013; Xie, Brayne, & Matthews, 2008). As the disease progresses, it becomes increasingly symptomatic with behavioral disturbances, overt psychiatric symptoms and severe communications deficits (Lyketsos et al., 2002; Rabins, Lyketsos & Steel, 2006; Tampi et al., 2011). These central study terms are further scrutinized throughout the course of this manuscript, and vital connections to relationship closeness elements, caregiving and dementia disease per se, are detailed.

### **Epidemiology of Dementia and Caregiving**

Our affinity for living longer is mirrored in current census data in which, the number of adults, aged 65 and older, in the United States, has increased from 20 million in 1970 to 40.2 million in 2010. Those numbers are expected to grow to more than 88.5 million in 2050 (Vincent & Velkoff, 2010; West, Cole, Goodkind, & He, 2014). Presently, a total of 5.3 million persons are diagnosed with dementia, and because Alzheimer's disease is an age-associated disease,

rising numbers will echo census data. Dementia is projected to increase by 50% over the next 20 years and to nearly triple by the year 2050. There is widespread agreement that forecasts a public health epidemic attributable to these statistics and their eventual cost and consequences to caregiving. The predicted increase in dementia will place more demands on the presence and accessibility of aging caregivers and cause a spiral spending of health care dollars and co-use of Medicare and Medicaid funding (Alzheimer's Association, 2017; World Health Organization, 2012). During the 2017 year, the United States is estimated to spend \$259 billion caring for individuals with Alzheimer's and related dementias; this is unsustainable. Moreover, this quarter trillion dollars being spent in no way effectively treats, prevents or cures this devastating disease. Approximately one out of five Medicare dollars is spent on a person with Alzheimer's (Alzheimer's Association, 2017).

Spousal caregivers provide over 50% of the national in-home dementia care. They delivered the maximum number of hours per week of direct care when compared to formal, informal, or other kin relations of persons with dementia. Spouses cared for chronically ill partners longer than adult children (Brodaty & Donkin, 2009; Institute of Medicine, 2008; Partnership for Solutions, 2004). They desired and used less home health services and community-based resources (Robinson, Buckwalter, & Reed, 2005). These facts and figures underline the exorbitant cost of dementia disease care and highlight the importance of the unpaid spouse caregiver; it also suggests a terrible and untenable circumstance in the future if we do not address dementia spouse care models soon.

Resilient spouse caregivers are at the nexus of dementia care, providing day to day care to a person with dementia and managing ever-changing life plans. They are the stewards of economical home care, the advocates of cultural competence and the gate-keepers to dementia

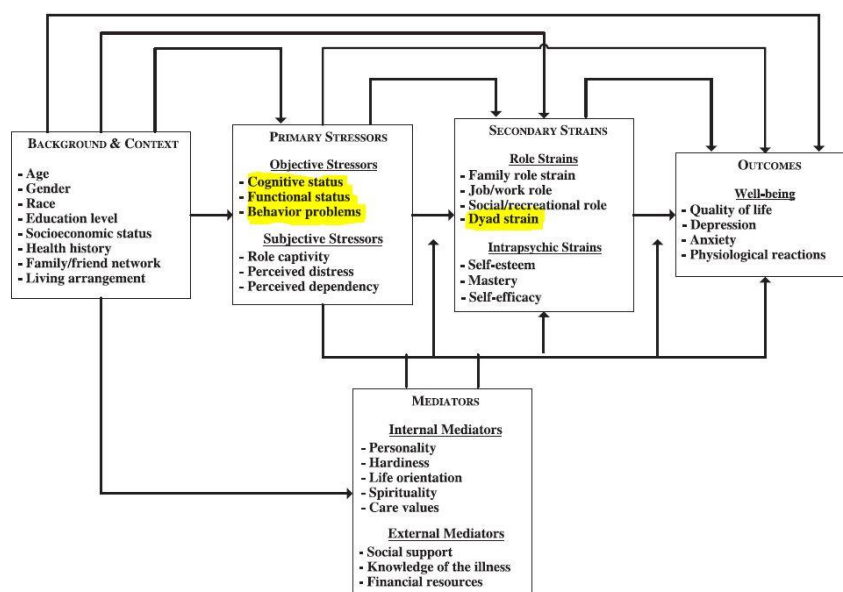
research (Alzheimer Association, 2004). Spousal caregiving is one-dimensional when used merely as a demographic variable; however, it allows greater interpretation when parsed as a cohort in comparative kin relationship studies and then related to outcomes such as burden, role captivity, or quality of life. The spouse demographic is a critical element in process oriented experimental research that guides caregiver efficacy and coping studies, and implementation of non-pharmacologic interventions.

However, for the spouse cohort alone, increasing age, stress, and burden ultimately resulted in more adverse health consequences of spouse caregiver when compared to adult child caregivers (Schulz & Martire, 2004; Seltzer & Li, 2000). Negative health consequences arising from spouses caring for their loved one with dementia can be severe. There is broad research related to adverse caregiver morbidities including depression and anxiety (Brodaty & Luscombe, 1998; Schulz, O'Brien, Bookwala, & Fleissner, 1995), heart and chronic kidney disease (Schulz & Martire, 2004; von Känel et al., 2012), slower wound healing (Kiecolt-Glaser, Marucha, Mercado, Malarkey, & Glaser, 1995), decreased preventive health practices (Hodgins, Wuest, & Malcom, 2011), poor sleep (McCurry, Logsdon, Teri, & Vitiello, 2007), hypercoagulability (von Känel, Dimsdale, Patterson, & Grant, 2003), adrenal stress response alteration (Vitaliano, Persson, Kiyak, Saini, & Echeverria, 2005) immune suppression (Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991; Vitaliano, Zhang & Scanlon, 2003), ironically, cognitive impairment (Vitaliano, Murphy, Young, Echeverria, & Borson, 2011), and even an increased mortality (Schulz & Beach, 1999). The most frequent triggers for a care-recipient's institutionalization are the primary caregiver's high stress, depression and sense of role captivity (Gaugler, Yu, Krichbaum, & Wyman, 2009).

Dementia disease triggers a loss of intimacy and control, neglect, and unpredictability which are all critical elements in the maintenance of a close relationship (Quayhagen & Quayhagen, 1996). Altered interpersonal communication including expressed emotions of anger, role renegotiation, and taxed coping skills often lead to chaos. The dementia caregiver and care-recipient relationship have a potentially harmful side, including injury to the dyad, dissolution of the couple and severe morbidity (Beach et al., 2005; Cantor, 1983; Walker & Luszcz, 2009; Williamson & Shaffer, 2001). In some cases, irreversible detachment may lead to early care-recipient death (Wright, Hickey, Buckwalter, & Clipp, 1995). Roberto, McCann, and Brossoie, (2013) found a limited documentation of intimate partner violence (IPV) in the setting of dementia. However, they reported 21% of all victims of homicide in general, committed by an intimate partner, were over 65. Murder-suicide IPV was found more frequent among older adults, of which the authors related to sickness, extreme interdependence, and IPV history. In another study, Brossoi, Roberto, and Barrow (2012) described 24 incidents of media reported IPV of both caregivers and care-recipients that resulted in assault, neglect, and homicide. The investigators found the deaths were related to caregiving stress, relationship tension and poor mental health, including dementia. Similarly, Melchiorre et al. (2016) reported most IPV victims were women but found men too were abused. They also informed IPV was significantly influenced by disability, poor health, and custodial needs. Intimate partner violence and its risk were under-recognized, detected and reported.

Changing roles and altered reciprocity caused resentment and hostility, and spousal reports edged from intimate towards alienated, all in response to dementia disease (Wuest, Ericson, & Stern, 1994). Spouses also identified the paradox of role change from husband-wife to adult-child, which had a major impact on RC, attachment, caregiver behaviors and

implications for the caregiver and care-recipient's mental health. Persons with dementia were individually subject to enormous stress from dementia disease, and it was characterized as a primary stressor (Pearlin, Mullan, Semple, & Skaff, 1990). Judge, Menne, and Whitlach (2010) further investigated this stress model. The authors suggested one-way links between a person with dementia's objective stressors of the dementia disease (cognitive and functional status and behavior problems), with a secondary dyad strain and potential adverse outcomes for the care-recipient's quality of life, depression, anxiety and physiological reaction. Dyad strain was measured by family conflict and positive and negative emotions related to caregiving. It was reported as a dyadic intrapsychic strain characterized as internal self-perceptions and feelings. The authors described a vital discovery: although secondary strains occurred, the consequences were not secondary in importance. To illustrate this interrelatedness of a person with dementia and overflow to a secondary dyadic strain, a diagrammatic model is shown below in Figure 1.



*Reproduced with permission Judge, Menne, and Whitlach (2010)*

*Figure 1. Stress process model for individuals with dementia.*

Still, researchers have reported couples can be resilient, and they somehow manage to reconstruct a satisfying, if convenient and tolerable, marital relationship (LoboPrabhu, Molinari, Arlinghaus, Barr, & Lomax, 2005; Quayhagen & Quayhagen, 1996; Walker & Luszcz, 2009). Levine, Dastoor, and Gendron (1983) found humanistic beliefs among dementia caregivers that incorporated concepts of hope, duty, love, and compassion. They proposed those attributes were indicative of marital vows, and a strong motivation for successful coping with dementia.

Dementia and its unpredictable symptoms result in a loss of intimacy, companionship, and control, —all critical elements required to maintain a close mutually fulfilling spousal relationship. Since a marriage inherently merges both good and bad shared meaning with trends of lavish, as well as meager, companionship and material support, the couple faces further dramatic changes when confronted with dementia's losses.

Dementia is a transformative disease, In the severe stage, the disease heralds major care-recipient cognitive and functional impairments and increased caregiver relational deprivation. That relationship closeness is tested to find the personhood and remaining human values (Kitwood, 1993; Marwit & Meuser, 2002). All caregivers have the legacy of a relationship which evolves along a timeline simultaneous with, and responsive to the progression of dementia disease. This temporal aspect of caregiving for both caregiver and person with dementia suggests a variation of relationship closeness; it decreases in some ways, while it increases in other ways. There appears to be a threshold level at which 'good' RC improves caregiver and care-recipient outcomes, and 'low or poor' RC affected the care-recipient's expression of CI-NPS (Burgener & Twigg, 2002; Morris, Morris, & Britton, 1988).

Even in mild stage dementia, most caregivers identify losses in care-recipient cognitive and behavioral domains (such as spontaneity and meaningful dialog) which in turn varies the

couple's dynamics. Relationship closeness then can be viewed with an alternate lens having multiple diverse behavioral measures such as burden, shared activities, caregiver rewards, intimacy, cooperation, caregiver self-esteem and a host more. Relationship closeness is a complicated concept.

Consequently, those married seniors who live in community settings and develop dementia, depend on resilient spouse caregivers. In fact, that marital relationship is vital to the overall health and wellness, safety, and quality of life of the dementia diagnosed partner. It, nevertheless, impacts the core of the marital relationship concepts of affection, communication, interdependence, and mutuality for both dyad members. The following section describes those concepts in greater depth.

### **Dementia and Dyad Theoretical Foundations**

To allow the readers a full comprehension of the context of dementia caregivers' relationship with their spouse, three conceptual models fundamental to dementia and marriage, are described: personhood in dementia, interdependence, and resilience. Though not underpinning this phenomenological study, these concepts are integral for readers to understand the scaffolding of relationship dynamics that are vulnerable once dementia occurs. The concepts allow the reader an empathetic basis to recognize and fully grasp the challenges of spouse roles, marital relationship, and dementia caregiving.

**Personhood in dementia.** Dementia can be viewed from multiple perspectives: biomedical, social, political and philosophical. The current and most prevalent construction of dementia is through medicalization. This view sees physiologic symptoms and pathological changes of cerebral tissue causing  $\beta$ -amyloid plaques and neurofibrillary tangles. Accordingly, the technical orientation of medicine reduces a patient's experience with dementia, to a label,

i.e.: a diagnosis and code which then logically focuses on a cure. There is a fundamental connection between cause, cure, and treatment in the medical model that limits individuality (Kitwood, 1993; Mayo, 2013). For example, neurologists, psychiatrists, and neuropsychologists apply an empiric methodology to comprehend, diagnose and treat physical and mental health symptomatology, all in a forward momentum, but without a definitive diagnosis until absolute pathologic testing is completed at autopsy (Davis, 2004). It is clinically oriented, yet ambiguous at the same time.

With dementia, we find medicalized care has inherent problems. The longitudinal Nun Study focused on the lives, aging, and neuropathology of 678 Catholic sisters. The nun's case histories presented a broad range in cognitive and physical function and neuropathology. It was found that dementia symptoms vs. healthy aging depended on the individual's degree of pathology in the brain vs. the degree of resistance to the clinical expression of the pathology. Some participants had substantial neuropathology but few, if any, dementia symptoms. These findings suggested a capacity to resist pathology (Snowden, 2003) that in turn confused diagnosis. Comprehensive dementia diagnosis, treatment, and care using the medicalized paradigm is inexact.

Turning away from the biomedical care model, Kitwood (1993) re-conceptualized dementia beyond the traditional viewpoint. He stylized a contextual framework for the person with dementia; in other words, he emphasized personhood, specifically personality and biography. He argued that dementia caregiving is an engagement that is based on cooperation and reciprocity. He proposed a focused program based on a person-centered theoretical model as an attempt to explain the needs and interpersonal bonds connecting caregiver to care-recipient. Kitwood described the continual interplay between neuropathologic load, physical and functional



factors and social-psychological elements of biography and lifestyle. He called them the ‘dialectics of dementia’ (Dewing, 2008; Kitwood, 1993).

This new culture of person-centered dementia care urges us to respect the individuality of people with dementia. Kitwood’s conceptual basis acknowledged that embracing personhood allows good and proper care. His framework suggests the clinical manifestation of dementia symptoms can arise at any time point. The expression of dementia symptoms is a function of a complex interaction of five factors: personality, biography, health status, neurologic impairment and social psychology. Parsing the five factors is a way of learning the uniqueness of a person with dementia, as the disease continually advances paring away at memory and judgment, and stability and security. “Personhood can only be guaranteed, replenished and sustained through what others provide” (as cited in Kitwood, 1993, p. 545). A personhood perspective argues that until a definitive cure is established, dementia science, treatment, and research should be grounded with respect to the person as an individual and how they live and experience dementia.

**Interdependence.** Kelley & Thibaut (1978), first introduced interdependence theory as reciprocal interactions between couples and described it as the essence of close relationships. They defined interaction in that one spouse emits a certain behavior in the presence of both members of the dyad. Essentially, the couple’s interaction is executed by communication, creation, and co-creation of products in the form of costs and rewards. These costs and rewards “end-products” can be visceral, emotional and physical actions like pleasure, gratification, distress, pain, hug, hit, smile, embarrassment and a host of others, as well as those possible or potential, future ‘unknow-yet’ feedbacks. Similarly, another dyadic theory, the investment model of commitment (Rusbult & Buunk, 1993) also addresses the interpersonal action and reaction between partners. It suggests that interdependence is felt as a committed engagement,

characterized by a desire to maintain the relationship through good times and bad. Rusbult and Buunk (1993) aptly write, "The theory is especially concerned with the structure of interdependence between two individuals, which rests on the ability of each partner to influence the other's outcomes" (p. 178). For example, simple preventive health expectations from a spouse may precipitate their husband's or wife's healthy lifestyle of tobacco cessation and exercise. Alternatively, a spouse's income may allow the other early retirement. Likewise, the termination of a husband's driving may impact how functional and participative the wife may become. In summary, the marital vows taken seriously by a spouse may allow an instinctive perseverance thru catastrophes.

Wright (1994), used these interdependence theories as a framework to describe dementia's influence. She found a significant association between positive dementia spousal interactions, high caregiver commitment and investment, and favorable outcomes in persons with dementia. Interdependence theory, then, suggests that dementia dyads become more interdependent over the course of their marriage. As interdependence increases so do concern for the spouses' outcomes, i.e.: prognosis, comfort, dignity and quality of life (Norton et al., 2009). When looking at interdependence theory conceptually as a scale, investments made in the dementia dyad tip the scale wholly by spouse caregivers' sacrifices (Norton et al., 2009). The transformation of motives then follows, from self-interest early in the marriage, to a pro-relationship motive in couplehood that would explain positive persevering behaviors in dyadic dementia relationships (Lewis et al., 2006).

**Resilience.** The contemporary meaning of the word *resilience* is the ability to spring back; resume a previous shape after bending or compression; to readily recover from shock, depression, adversity, or the like (Dictionary.com, 2017). In our current language, resilience

explains an innate ability to roll with the punches and cope with negative and positive life events (Dryden, 2005). Polk (1979) proposed a concept synthesis of resilience. She conceptualized the characteristics of those who can rise above adversity, by any or all constructs of personal disposition, personal roles, the capacity to act and react in certain situations, and a philosophical self-knowledge belief. She reported that resilience is a complicated concept of which the defining characteristics are patterns: 1) dispositional: intelligence, health, temperament, and self-efficacy and esteem, 2) relational: the value attributed to interpersonal relationship, 3) situational: characteristic abilities in the face of stressors, problem-solving, flexibility, perseverance, resourcefulness, and capacity to act, and 4) philosophical: personal beliefs and self-knowledge (Polk, 1997). Using similar defining patterns, Harmell, Chattillion, Roepke, and Mausbach (2011) studied resilience in dementia caregiving. They used three broad resilience domains: personal mastery, self-efficacy, and coping style as variables in their research. Their main findings were that higher levels of personal mastery and self-efficacy, and increased use of positive coping strategies, suggested a protective effect on health outcomes in dementia caregivers, specifically: anger and depression.

To further explore resilience and couplehood, Fergus (2015) described the “WE-ness” of a couple. She described dyads, who, when confronted with dementia, their goal was to try to retain relationship closeness. However, the more she looked at relationship dyads, the abstractness and ambiguity of “we” in dementia dyads became further evident. The author found the “we” in dementia to be elusive, yet at the same time, profound and powerful. According to Fergus, language and communication contributed significantly to couplehood, but by no means exclusively explain the dyad's identity. A shared narrative and life-meaning, a couple's own

personal language and reminiscence allowed a robust collective identity of the couple, co-construction of couplehood, and caregiver resilience.

Research on the negative aspects of caregiving or, a “wear and tear” hypothesis, proposed an adaptation effect. Uplifts in caregiving and the benefits and psychological rewards of being a caregiver have also been studied. These combined findings suggested the presence of resilience and the innate ability to persevere as a dementia caregiver (Gaugler, Kane and Newcomer, 2007).

### **The Significance of the Phenomenon Under Study**

Dementia heralds the advent of new spousal roles as caregiver, personal advocate and language communicator for the impaired partner, while at the same time there is an ever-increasing pervasive sense of ambiguous grief clouding the marital relationship and its future. Marital lifestyle changes in a myriad of ways in response to dementia, thus contributing to the rise of intimacy, reciprocity, and communication issues. It prompts spouse caregiver feelings of inadequacy, marriage failure, hopelessness, embarrassment, and sometimes a desire for widowhood. However, by some extraordinary means, couples endure, and successfully reframe their marital, social bond through what is thought to be an acclimatizing relationship closeness.

In summary, the importance of the spouse caregiver relationship closeness and dementia disease phenomenon which the author chose to study, was critical to identify at the very outset of dissertation planning. It was the foundation, the reason d'être of the phenomenological study. It steered the author towards phenomenological philosophy and psychology. Relationship closeness in spouses of dementia caregivers is complicated, and not easily understood by measurement with common marital satisfaction surveys. Instrumental measures fail to capture the essence of marital dyads' relationship, and its changes as well as its exceptionalism, in the face of a

depersonalizing disease. Dementia symptoms related to cognitive impairment: memory loss, poor recognition of family members, and speech and language disorders hinders communication are at the very heart, literally and figuratively, of marriage and relationship closeness.

Additionally, neuropsychiatric symptoms of mood changes, delusions and psychoses are strange and frightening behaviors, likely never displayed before by their spouse before the dementia diagnosis. The upshot is a complicated tapestry weaving a new dementia language and behaviors with the dynamics of traditional couplehood and marriage.

Dementia couplehood concepts reflect a dynamic reality best examined with a deep qualitative lens. Munhall (2007) and Benoliel (1984) differentiate appropriateness of qualitative research versus scientific methods when the topic of interest concerns perceptions of social life, is fluid and changing, where there may be multiple realities, where the participants are active agents, and where *no response* bias on instruments is highly predictable. Dilthey was a preeminent 19<sup>th</sup>-century philosopher best known for distinguishing natural science from human sciences. He suggested methodologies are based on the fundamental attitude and approach with which you would investigate objects. Natural sciences look from the outside inward seeking causal explanations, prediction, and control, and the human sciences depend on the inside to outward perspective in quest of understanding, interpretation, and meaning (Makkreel, 2016; Munhall, 2007).

Thus a qualitative investigation approach is the most appropriate and reasonable method to study spouse caregiver RC and dementia disease. Therefore, the goals of this proposal are to improve the depth, breadth, and rigor of dementia caregiver spouse studies; correctly record the spouse caregivers' perception of relationship closeness in the context of CI-NPS, and contribute to the art of nursing and scientific research. Although phenomenological studies do not allow

generalizability, the study outcomes may provide a scaffolding for further research to develop, re-imagine and use valid relationship closeness descriptions and findings to improve families' quality of life and provide information allowing clinicians to intervene, treat and manage dementia symptomatology.

### **The Phenomenological Approach and Study Research Questions**

The purpose of this descriptive phenomenological study was to investigate the schema of spouse caregiver relationship closeness with an underlying focus of dementia disease's cognitive impairment and neuropsychiatric symptoms. This inquiry merged marital RC with the sequelae of dementia symptoms and behaviors. The research questions were what is the fundamental structure of the phenomenon, and what is the meaning of the experience of the phenomenon? The fundamental structure, a term used by Colaizzi (1978a, b) was described as a reflective reduction of author and participant narratives, from exhaustive descriptions to its most common, essential constituents of the experience. Using a mathematical metaphor, it is the common denominators; i.e.: themes, descriptors or elements, that all of the spouse caregivers shared. Because a comprehensive meaning of the phenomenon would require intense and profound exploration, immense practical considerations of time, volumes of dialog, serialized interviews and extensive data, the author instead focused on one aspect of the phenomenological meaning of relationship closeness, that of RC variation in response to the dementia journey.

This study of marital relationship closeness used a Husserlian eidetic method and Colaizzi empirical reflection process to focus, analyze and dwell on memories and experiences of relationship closeness concepts described by caregivers as their spouse expressed dementia disease cognitive impairment and neuropsychiatric symptoms in the ordinary course of day to day living. The analysis allowed the voice of the spouse caregiver to richly illustrate a personal

narrative of their own RC in context with dementia. The fundamental structure and meaning of the relationship closeness embedded in the experience of spouse dementia caregiving challenged with a partner's cognitive impairment, neuropsychiatric symptoms, and functional loss, provided an indication of their lifeworld. We as health care providers are not privy to this life's view during clinical visits. It is not a concept clinicians exercise in care models, nor is it framed in the typical medicalization of dementia diagnosis and treatment of CI-NPS.

### **Dissertation Overview**

This chapter presented the reader with the basic concepts and theoretical foundations integral to understanding dementia and dementia spouse caregiving. It shed light on the marital paradigm in the face of a disease whose symptoms damage many of the elements we commonly associate with RC. Relationship closeness was introduced, and the significance of the phenomenon was illustrated. In summary, the aim of the descriptive phenomenological study was to explore the narrative of caregiving spouses' relationship closeness in the face of neurocognitive and psychiatric symptoms of their spouse diagnosed with dementia.

Chapter two looks at a comprehensive review of the literature using a scoping method that links the dementia spouse caregiver's relationship closeness with dementia disease's cognitive impairment and neuropsychiatric symptoms. Chapter Three details the philosophical underpinnings and the methodology of the present study using Colaizzi's scholarship (1973, 1978a, b, 2001, 2004). The Colaizzi descriptive phenomenology and methodological roots are discussed, and the study design and related procedures are outlined. The co-researchers are introduced with a participant and spousal portrait. The various layers of the analytic process i.e.: discovery of the fundamental structure using Operation One: Individual Phenomenological Reflection (IPR), Operation Two: the emerged fundamental description from a multi-participant

phenomenal study and the multiple stages of the Empirical Phenomenological Reflection (Operations Three and Four) are defined. Chapter Four illustrates the analysis and findings of the current phenomenal study which is reflected as rich and exhaustive, and finally, details the discovered fundamental description of the research phenomenon. Chapter Five provides a discussion of the constituent elements, the fundamental structure of the phenomenon and a limited description of the meaning of the phenomenon. To capture the applicability of this research project, the conclusion blends and summarizes the study outcomes, limitations, the impact on the author's personal nursing practice, and lastly, considers the study's contribution to further research and implications for wider application.



*I feel really alone. Even with him in the room, I'm alone.*

*It's almost like you are watching it.*

*I'm watching my husband go away from me.* Participant 007a

## **Chapter Two: Review of Literature**

Chapter Two of this dissertation details a study of the relevant works related to dementia dyads, relationship closeness, dementia disease, and caregiving. It looks at theory and literature, books and descriptive research, which in total, guided this study. Relationship closeness is deeply explored. To understand relationship closeness within a dementia dyad, the readers must be subject to the inquiry of related concepts including the conceptual theories related to a marriage entrenched in a dementia milieu, as well as dementia disease's nosology, and its explicit and implicit effects. The limited, current state of the science of relationship closeness and dementia marital dyads is reviewed. Recent scientific studies that investigated parsed elements of RC- a myriad of independent and dependent variables and diverse outcomes, that linked relationship closeness in a dynamic relationship with spouse caregivers, caregiving outcomes, and/or dementia's CI-NPS are described. This review reinforces the rationale and research methodology for the current study.

The literature review procedure for this chapter is based on the author's integrative review (Schjavadland, 2015). It employed similar search criteria using PubMed, CINAHL+, and PsychInfo databases and the search engine Google Scholar. It included peer-reviewed, English publications from 1984 to 2016. The keywords used to develop search algorithms were: relationship closeness, caregiver, and dementia neuropsychiatric symptoms, and their generic equivalents. Relationship closeness was ill-defined and a conceptually broad term in research,

therefore different concepts such as relationship intimacy, bond, quality, satisfaction, communal behaviors, adaptability, and cohesion were used to capture interpersonal dyadic relationship.

### **Introduction to Dementia Caregiving and Dyads**

Caregiving is a rich study area from a multitude of natural science and humanistic disciplines. Discussion of dementia caregiving also encompasses the domains of caregiver efficacy, the cost of care, and positive and negative outcomes of dementia caregiving. Experimental research tackles caregiving with interventional trials prioritizing the need for education, use of home health services and community resources, cultural differences, and even reasons for institutionalization. Additionally, dementia caregiving studies address adaptability and appraisal abilities among caregivers, clarify differences among personality, types of attachment and caregiving types, use of support groups, and spiritual and culture diversity.

Dementia caregiving is linked with future economics, Medicare and Medicaid spending, financial losses to patient and family, the monetary cost of indirect caregiving, and lost wages (Alzheimer's Association, 2013, 2017; MetLife, 2006). Lastly, positive outcomes of spousal dementia caregiving reflect a capacity to preserve satisfaction, reframe marriage, sustain meaningful lives, and even theorize positive gains, mutuality, and transcendence, thus a sound and beneficial relationship closeness.

### **Relationship Closeness**

All marriages, with and without dementia or chronic illness, reveal relationship closeness. This construct and its concepts change over time, moving along a continuum with Erikson stages of adult psychosocial development; they include intimacy vs. isolation, generativity vs. stagnation and ego integrity vs. despair (Brown & Lewis, 2003; Erikson, 1963). Relationship closeness within the marriage is challenged with stress processes, and both husband and wife

respond to those strains by conveying both mechanical (i.e.: behaviorally and ritually), as well as intentional coping skills (Bliezner & De Vries, 2001). Normal marriage ‘work’ is evidenced by role allocation, intimacy and a developed identity as a couple, previously referred to as the “we” or “we-ness” and “couplehood” (Brown & Lowis, 2003; Fergus, 2015).

Relationship closeness is often imprecisely defined in research, uses generic, non-specific terms, and lacks vigorous concept analysis. First, relationship closeness is itself an autological term, and it lacks consistency as an instrumental research measure. Keyword search terms investigating relationship closeness must include “closeness,” as well as, bond, communication, quality, satisfaction, intimacy, mutuality, continuity, and various other terms. As a research variable, relationship closeness is infrequently examined in important dementia research projects and non-pharmacological intervention studies. When RC is used as a variable, the instrument is often co-opted from “normal marriage” research and counseling using elements of love, closeness, intimacy and nearness (Mangen, Bengtson, & Landry, 1988). This causes a host of terminology and taxonomy challenges and confusion in dementia research.

Relationship closeness is a construct within the marriage and incorporates a variety of possible conceptual dimensions such as affection, aesthetics, commitment, emotion, mutuality, physical intimacy, joint activities and recreation, shared social contacts, sexuality, religiosity-spirituality, and intellectual characteristics (Bliezner & De Vries, 2001; Quinn, Clare, & Woods, 2009; Whitlach, Schur, Noelker, Ejaz, & Looman, 2001). Affection can be further deconstructed into love, respect, trust, appreciation, and recognition (Fauth et al., 2012).

Within the marriage, verbal and tactile communication is also an essential contributor to physical, affective and cognitive closeness (Gleeson & Timmoms, 2004; Savundranayagam & Orange, 2011). Weiss and Heyman (1997) reported communication skills as significant

predictors of marital satisfaction and patterns of effective communication. How spouses speak and act are critically related to relationship quality and marital happiness (Litzinger & Gordon, 2005). Verbal communication is a common and essential element in RC instruments, but it is confusingly juxtaposed with the advent of speech and communication problems that are early dementia symptoms. Verbal communication is a critically measured element in relationship closeness, but what does it tell and how can it guide, when dementia disease often progresses to aphasic syndromes? Relationship closeness can also be viewed with an alternate lens via other behavioral measures such as burden, shared activities, caregiver rewards, and self-esteem.

Touch is fundamental to communication (Buckle, 2009), and is an important and meaningful part of marital intimacy. Touch implies and is indicative of closeness and intimacy (Edvardsson, Sandman & Rasmussen, 2003). Touch is experienced both physically and sensorily, but also affectively as an emotion and behavior. The nervous system functions holistically, so the interaction of touch affects the autonomic, reticular, and limbic systems, and consequently, influences the emotional responses and drives with profound effects (Huss, 1977). Expressive, also called non-necessary touch, is an emotional, reassuring and physical contact (e.g.: to hug, pat, stroke, kiss) to all humans of all ages. It may have connotations of familiarity, recognition, caring or sexual intimacy. Expressive touch conveys emotions and is the opposite of instrumental touch. Instrumental touch is termed task or necessary touch (e.g.: to dress, groom, feed, reposition, wash). Moreover, when dementia is at its worst, tactile communication is frequently used, and instrumental touch often displaces expressive touch.

Researchers reported that expressive and comfort touch is pivotal, critical and integral to providing care for persons with dementia (Edvardsson, Sandman & Rasmussen, 2003; Kim & Buschmann, 2004; Rose, 2010). As dementia disease progresses, care needs also increase

exponentially to include provision of the most basic activities of daily living. Additionally, possible medical treatments, such as topical administration of medications, hygiene and even wound care arise as necessary touch. With those requirements, the "normal" role of a spouse incorporates that of a paraprofessional healthcare provider. Task oriented procedures increase in frequency and complexity, and the conflicting roles of spouse vs. caregiver roles can be confusing, overtaxing, and at times, divisive. Despite the needs of task touch, expressive touch is still essential.

**Relationship Closeness Measurement.** Relationship closeness falls within a spectrum of casual to intimate. It is reciprocal in nature, dynamic and dimensional in a “give and take” paradigm (Mancini & Bliezner, 1992; Timmerman, 1991). Relationship quality in dementia spouse caregivers can also be viewed as oppositional. Pearlin et al. (1990) reported relationship closeness was construed as relational deprivation.

Current measurement strategies and instruments used by researchers do not capture the true essence of RC in the marital relationship. This limitation is amplified when dementia affects a spouse and is compounded further because different types of dementia disease have a unique biopsychosocial symptomatology and temporal progression of losses. It would seem then, there is a critical need for an alternative RC measure. Alzheimer’s disease RC requires evaluation in a special way that targets memory and contextual speech losses. Measurement of RC of caregivers of persons with frontal lobe dementia diseases must look differently at emotional expression, and lack thereof. Although there is a thread of common neurological deficits, signs, and symptoms among dementia disease typologies, each person with dementia expresses them distinctively and exclusively. That uniqueness is in keeping with Kitwood’s paradigm (1993) and dementia dialectics. Also, each care-recipient has strengths and weaknesses based on the type and acuity

and sparing of memory, executive, and visuospatial losses, as well as the degree and incidence of aphasia, apraxia, and agnosia, and the manifestation of neuropsychiatric symptoms.

Relationship closeness is currently measured by different parameters with both positive and negative attributions of closeness, intimacy, marital satisfaction instruments, sense of coherence, and cohesion scales. There is an assortment of surveys and validated instruments. In one study (Eloniemi-Sulkava et al., 2002) used an untested survey that measured happiness or general atmosphere in the relationship from 1) extremely warm to 5) very hostile, and the experienced happiness of marriage with choices from 1) perfectly happy to 5) very unhappy. The investigators recorded companionship in the dyad situation where either spouse acted like a head of the relationship, or more like a parent or a child than like a partner. The caregivers were also asked to evaluate how well their spouse had fulfilled their sexual expectations as a husband or wife before and after the onset of dementia on a 5-point scale with options ranging from 1) very well to 5) very poorly. The authors reported meaningful findings but with mixed significance ( $p < .001-.782$ ) and clearly illustrated the limitation of studies where RC elements were identified but not clearly defined, described or validated.

Other studies also measured RC quality using descriptive surveys designed by the authors. Relationship closeness was collected in general terms before and after the disease. Simpson & Carter (2010) studied the sleep quality of dementia caregivers but also collected data on the relationship. The quality of the caregiver's relationship (the past and present) was captured by asking the caregiver to describe the relationship on a scale from 1) conflict-ridden to 5) harmonious, before and after dementia. Another visual analog scale (de Vugt et al., 2003) provided variation from 0 (not good at all) to 10 (very good) in regard to how caregivers rated their overall present and past (before dementia) relationship. Relationship closeness can be

measured at the current moment, prospectively, and retrospectively (pre-dementia state), and a positive or negative net RC change can be calculated. The salient point is that a relationship existed before the illness (good or bad), and evolves (good, bad, or unchanged) as dementia impairment worsens.

There are four instruments used by most authors to measure pre-and post-relationship closeness in dementia dyads. The Burns Relationship Satisfaction Score (Burns, 1983) measures seven items: communication, conflict resolution, affection, caring, intimacy, closeness, and satisfaction. The Relationship Closeness Scale, a six-item instrument developed by Noelker (1996) and Whitlatch et al. (2001) reports on mutuality, general closeness, demands, specialness, criticism, and communication. The four items of the University of Southern California Longitudinal Study of Three-Generation Families Measures of Positive Affect (Mangen et al., 1988; Lawrence, Tennstedt & Assmann, 1998) captures a minimalist view of general closeness, communication, the similarity of opinion about life, and the perceived degree of getting along. Lastly, the Intimate Bond Measure Assessment (Wilhelm & Parker, 1988) identifies care vs. control, communication, kindness, understanding, domination, fun, affectionate, and critical nature. However, the bond measure was chiefly tested using a group of 33 combined control and psychiatric patients; its reliability was tested with 28 normal volunteers with an average age of 34 years old. This suggests only modest levels of reliability and validity, and without further testing has only a provisional application to aging couples.

These four combined RC measures are defined by preconceived constructs likely to predict neuroticism, outcomes from therapeutic interventions, and marital dissatisfaction (Mangen et al., 1988; Lawrence et al., 1998; Wilhelm & Parker, 1988). It is important to note that relationship closeness instruments are adopted from research examining non-dementia

couples and that unidimensional test element answers are given in only positive or negative terms without an ability to identify exceptionalism. A table of RC instruments and their measured critical elements is provided in Appendix A.

Now knowing the fundamentals of relationship closeness, concepts of dementia disease are discussed. Some of the very symptoms of dementia symptomatology are at odds with RC measures, not applicable, or would likely have a no response. Most notably, the instruments lack the free text to describe the exceptionalism of RC in a dementia dyad.

### **Dementia: A Syndrome**

Dementia originates from the Latin word *demens*, which translates to without mind or senses, out of one's mind, and madness (Dictionary.com). Berrios (1987) traced the concept of dementia to the 17<sup>th</sup>-century, and it had both legal and medical connotations. It described people who lacked competence and could not manage their affairs and finances without assistance from family, conservator or lawyer. With the advent of 19<sup>th</sup>-century medicine, the concept of dementia transformed and had an emphasized clinical implication. Severe failure of almost any mental function at that time was recognized to cause terminal states of behavioral incompetence. These medical diagnoses included head injuries, apoplexy, fits, dementia praecox (schizophrenia), melancholy, and other diseases of the cerebrum (Berrios, 1987). In 1906, Alois Alzheimer identified the presence of senile plaques, and neurofibrillary tangles in stained pathology slides post-autopsy of the famous Case #1, Auguste Deter. His research was published (Alzheimer, 1907, 1911) and he was given credit for such hallmark findings, and the disorder was coined "Alzheimer disease" as published in the famous neuropathology text by Dr. Kraepelin in 1910 (Whitehouse et al., 2000).

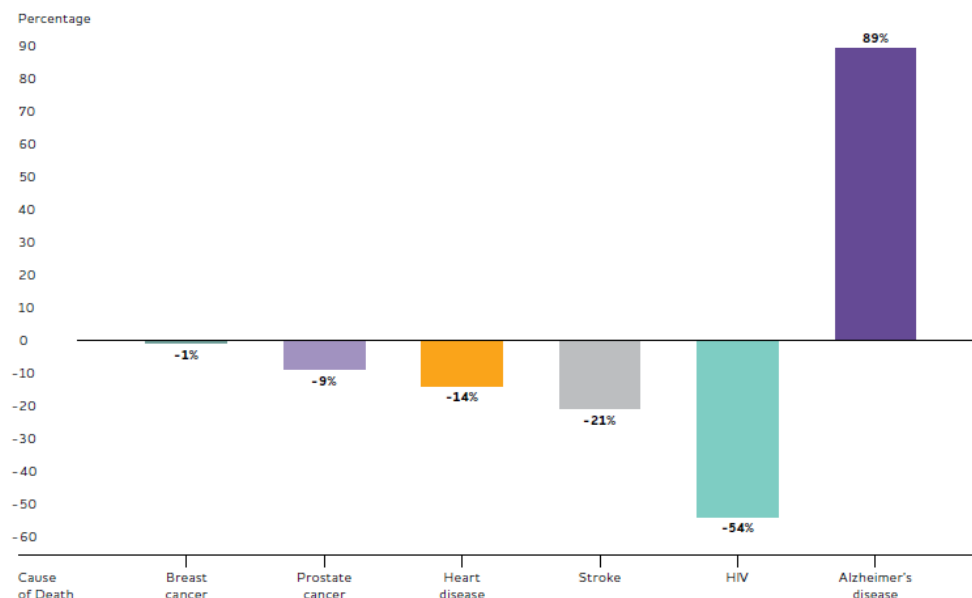


Today, dementia is defined as a syndrome and an acquired disorder rather than a specific illness. The syndrome consists of 2 or more impaired cognitive domains that prevent an affected person from functioning normally in society. The affected persons have “clear consciousness” meaning there is an absence of medical or neuropsychiatric problems like coma (problems with alertness or attention), or psychoses of schizophrenia, depression and bipolar disease (Dickerson & Atri, 2014; Rabins & Pearlson, 2009). Requiring instrumental and activities of daily living losses distinguish dementia from mild cognitive impairment, and intact alertness and attention distinguish dementia from delirium.

Dementia is often described as a generic umbrella of terms, under which, reversible and non-reversible diseases are listed. Reversible dementias will only be discussed regarding diagnostic evaluation. Non-reversible dementias include Alzheimer’s disease (AD), the most common dementia, vascular dementia (VaD), Lewy body dementia (LBD), Parkinson’s disease dementia (PDD) and frontotemporal degeneration dementia- with the subtype behavioral variant (FTD-bv). Clinical differential diagnosis is problematic in early stages because of shared symptomatology and multiple underlying causes and types complicating the clinical presentation. Clinicians are finding vascular dementia and Alzheimer’s disease, a so-called mixed dementia, emerging with more frequent regularity.

Dementia can begin at any age but is a predominant syndrome of later life. The prevalence in people older than 65 years is estimated at 9-13% with an annual incidence rate of 0.25% at age 65, that doubles every five years (Alzheimer’s Association, 2017; Rabins & Blass, 2014). One in ten people over the age of 65 in the United States has a form of dementia. Almost two-thirds of Americans with Alzheimer’s are women. Furthermore, Alzheimer’s disease is the sixth leading cause of death for all ages in America and the 5<sup>th</sup> most common cause of death for

people over 65 (Alzheimer's Association, 2017). It is the only top US disease which epidemiologically, has not improved with cure or control in ways similar to heart disease and cancer (Figure 2). Dementia disease statistically continues to grow in the face of increased incidence, frequently halted disease modifying research trials, and terminal progression (Alzheimer's 2017).



As cited in 2017 Alzheimer's disease facts and figures, p. 28. Alzheimer's Association (2017)

*Figure 2.* Percentage changes in selected causes of death (all ages) between 2000 and 2014.

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The diagnosis of dementia according to the International Classification of Diseases-10 criteria (World Health Organization, 1992) is a syndrome due to a brain disease. It is usually of a chronic or progressive nature, where there is a disturbance of higher cortical functions including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgment. There is no clouded level of consciousness (Lyketsos, 2007). Historically, the Diagnostic and Statistical Manual of Mental Disorders/DSM IIIR and IVR (American Psychiatric Association, 1987) operationalized the criteria for dementia, and later added the

critical elements of the Alzheimer's disease type (American Psychiatric Association, 2000).

They included the definitive loss of memory: short term forgetfulness (unable to remember three objects after five minutes), long term, and semantic memory loss; and at least one of the following cognitive disturbances:

1. aphasia, anomia and the loss of speech and language often seen as hesitancy, repetition, losing track of conversation, inarticulation, or jumbled, out of context conversations;
2. apraxia, the inability to translate voluntary command into a purposeful movement, for example zipping or buttoning clothes, the use of the spoon, or in severe dementia stages, the hesitation of toileting, sitting and self-feeding actions;
3. agnosia, failing to recognize object or people, getting lost, or anosognosia, the affected person failing to acknowledge that that he or she has a significant cognitive problem or dementia diagnosis; or,
4. executive dysfunction such as failing to manage daily living needs requiring meta-thinking, arithmetic, planning, and judgment (Ames, Burns & O'Brien, 2010; Dickerson & Atri, 2014).

The DSM, version 5 (2013), has replaced the word "dementia" with the phrase "neurocognitive disorder" to broaden the ability to diagnose and at the same time, destigmatized the syndrome. Their criteria now include the combination of one or more acquired significant impairments, along with lost independence:

1. cognitive domains such as complex attention, executive function, learning and memory (amnesia),
2. language (aphasia),
3. perceptual motor (visuospatial, praxis), or

#### 4. social cognition (recognition, emotions, behavior).

The new criteria take a more experiential view. Factors in biographical information from the client themselves vs. just testing, and use of contributing evidence from a knowledgeable informant, like family or caregivers, now become empiric data. Despite dementia's rapid or slow onset, its' salient feature is that there is always progressive decline over time.

Dementia diagnosis is accomplished through a robust medical history review, comprehensive physical exam, brain imaging, laboratory screening and diagnostic, cognitive testing and or neuropsychiatric testing. Health providers rule out metabolic, mental health issues like substance use, anxiety, stress, post-traumatic stress, depression or late onset schizophrenia, and comorbid causes like sleep disruption, polypharmacy, and so forth, as causes for the observed dementia symptomatology. There are some potentially reversible reasons, but only 1-2% of these patients presenting with dementia have a disorder, such as normal pressure hydrocephalus, medication-induced cognitive impairment, vitamin disorders, hypothyroidism, or major depression (Rabins & Blass, 2014).

There are essentially three stages of dementia described as mild (or early), moderate, and severe (or late) stages (Ames, Burns & O'Brien, 2010). Scientists studying dementia propose dementia actually presents twenty years before the expression of symptoms in the first stage is ever recognized (Alzheimer's Association, 2017). The pre-disease cerebral brain tissue changes are present and identifiable and are termed pre-clinical dementia, subjective cognitive impairment with or without mild behavioral impairment, or mild cognitive impairment. However, diagnosis of this early pre-stage of dementia with blood and cerebrospinal fluid  $\beta$ -amyloid and tau biomarkers, and  $\beta$ -amyloid and tau load on PET scans, are only used in Alzheimer's disease and related dementia research (Rabins, Graff-Radford, Small, & Yaari

(2009). Therefore, persons with dementia and their caregivers primarily rely on medical assessment and health history for a clinical diagnosis at a mild or moderate stage of the disease.

Several types of dementia exist as previously noted. Further discussion is limited to the most commonly found dementias: Alzheimer's disease, vascular dementia, Lewy body dementia, Parkinson's disease dementia and frontotemporal dementia. There are some salient symptoms and distinguishing characteristics for each type of dementia, but it is common for persons with dementia to have multiple and diverse CI-NPS. Any dementia can coexist with other dementias in a mixed status. Dementia types are identified in Table 1.

Table 1.  
*Types of Dementia*

| Dementia Type                      | History  | Signs and Symptoms  | Pathology/Imaging   |
|------------------------------------|--|---|---|
| Alzheimer's disease (AD)<br>60-80% | Gradual, progressive onset<br>Mean survival<br>4.2 years for men<br>5.7 years for women  | <ul style="list-style-type: none"> <li>• Memory loss, especially for names and recent events</li> <li>• Language deficits</li> <li>• Rapid forgetting</li> <li>• Impaired visuospatial skills</li> <li>• Normal gait and neuro exam during mild stage</li> <li>• Affective disturbances; NPS</li> </ul>   | Generalized atrophy, especially medial temporal<br>Neuritic plaques: extracellular, beta-amyloid<br>Neurofibrillary tangles: Intracellular inclusion bodies, hyperphosphorylated tau protein<br>Loss of cholinergic neurons in critical areas: hippocampus, frontal cortex, parietal cortex |
| Vascular dementia (VaD)<br>20-30%  | Variable or abrupt onset<br>Fluctuating course<br>Stepwise deterioration<br>May be gradual like AD<br>Median survival<br>3.3 years | <ul style="list-style-type: none"> <li>• Focal neurological signs</li> <li>-Hemiparesis-hemisensory deficits</li> <li>-Hyperreflexia</li> <li>-Extensor plantar response</li> <li>-Incontinence</li> <li>-Pseudobulbar palsy</li> <li>-Gait abnormalities</li> <li>-Visual deficits</li> <li>• Executive dysfunction</li> <li>• Signs of systemic and cardiovascular disease</li> </ul> | Multi and strategic infarcts<br>Lacunar infarcts<br>White matter lesions<br>Small vessel disease<br>Ischemic, hypoxic changes   |
| Lewy body dementia (DLB)<br>10-25% | Insidious, progressive with fluctuations<br>Occurs before or 1-2 years after Parkinson disease                                     | <ul style="list-style-type: none"> <li>• Fluctuation cognition</li> <li>• Visual hallucinations</li> <li>• Neuroleptic sensitivity</li> </ul>   | Generalized atrophy<br>Lewy Bodies<br>Cytoplasmic inclusions, defining lesion in the substantia nigra of patient with (PD)  |

|   |   |  |  |
|---|---|--|--|
|   | M: F ratio 2:1  | <ul style="list-style-type: none"> <li>• Parkinsonism: shuffling gait, increased tone, hypomimia, tremors, falls</li> <li>• Memory impaired later in the disease</li> <li>• REM sleep disorder</li> </ul>  | May also be found in the cortex (DLB)<br>Alpha-synuclein and ubiquitin               |
| Parkinson's disease (PD) dementia (PDD)<br>3-5%                                 | Insidious<br>30% of patients with Parkinson's will get dementia | <ul style="list-style-type: none"> <li>• Rapid cognitive decline</li> <li>• Apathy</li> <li>• Confusion may be related to Parkinson's drugs</li> </ul>   | Reduced hippocampal<br>Lewy bodies<br>Higher rate of atrophy compared to Parkinson's |
| Frontotemporal degeneration (FTD) subtype: Behavioral variant (FTDbv)<br>10-15% | Insidious;<br>Typically, in 50-60's<br>Rapid progression        | <ul style="list-style-type: none"> <li>• Disinhibition</li> <li>• Socially inappropriate behavior</li> <li>• Poor judgment</li> <li>• Apathy decreased motivation</li> <li>• Poor executive function</li> <li>• Preserved memory</li> <li>• Lack of empathy</li> <li>• Emotional lability</li> </ul> | Frontal and temporal atrophy<br>Pick cells and pick bodies in cortex                 |

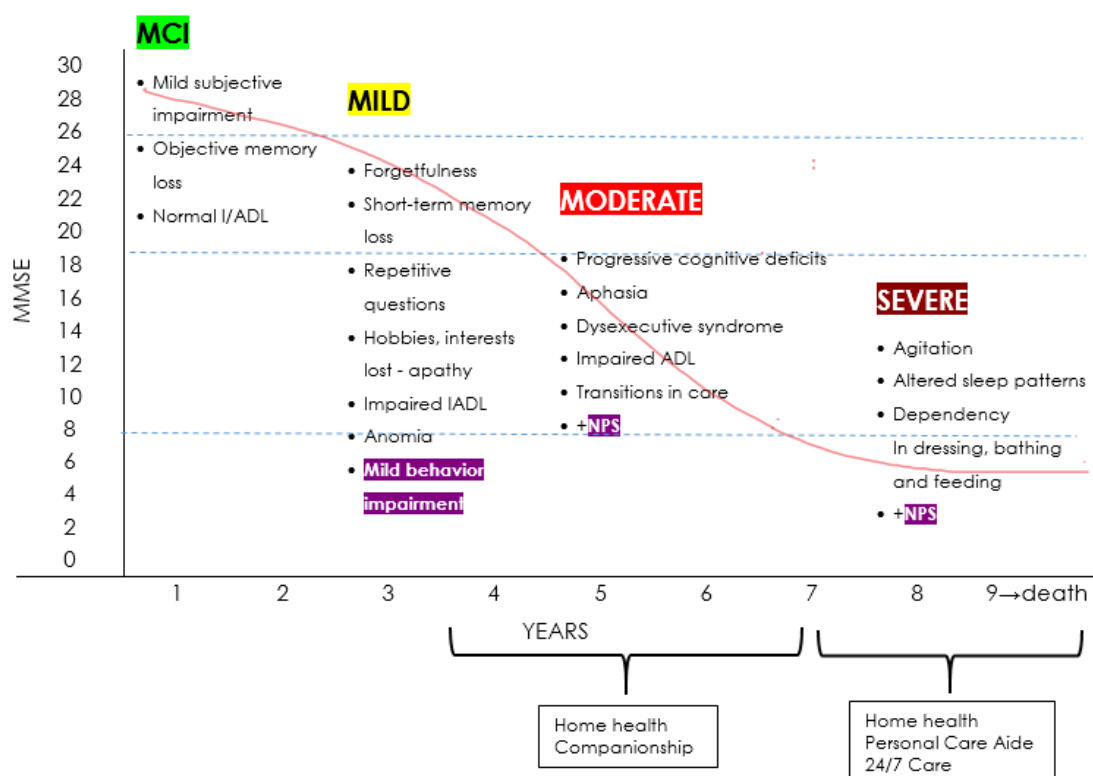
*Adapted from: Miller and Boeve (2016)*

*Additional Sources: Ames, Burns, & O'Brien, 2010; Dickerson & Atri, 2014*

Alzheimer's disease is a fatal and incurable neurodegenerative disorder. Because it is the most common type of dementia, the name Alzheimer's disease has incorrectly become synonymous with dementia. Definitive diagnosis can only be made post-mortem with pathological examination of brain tissue to identify protein abnormalities. The causes of Alzheimer's abnormal protein embedded in cerebral tissue and resulting neural cell tangles are unknown. The most common theory continues to be the amyloid hypothesis in which amyloid is cleaved prematurely by  $\alpha$ -secretase, thus collects as a sticky compound accumulating in the brain tissue and disrupting normal communication between neural cells. The  $\beta$ -amyloid eventually kills the surrounding brain tissue resulting in neurofibrillary tangles. Research is struggling with  $\beta$ -amyloid removal, generating immune system antibodies as active or passive vaccines, and developing natural anti-amyloid antibodies from intravenous immunoglobulin (Ames, Burns, & O'Brien, 2010; Dickerson & Atri, 2014).

In summary, dementia diagnosis in the living is often delayed because of complicated disease presentation, inadequate access to trained health providers and memory centers of excellence, and lack of family advocacy to persevere through a lengthy diagnostic evaluation. It is not surprising then there is a delay in appropriate management of persons with dementia, providing support to family caregivers and engaging the dementia family in proper care.

Alzheimer's is most commonly discussed according to its progressive stage, functional losses, cognitive impairment symptomatology, and NPS specific behaviors. Dementia progression according to the stage, a common cognitive test: The Mini-Mental Status Examination-MMSE (Folstein, Folstein, & McHugh, 1975), and symptoms are illustrated in Figure 3.



I/ADL: Instrumental and Activities of Daily Living; MCI: Mild cognitive impairment;  
MMSE: Mini-mental status exam; NPS: Neuropsychiatric symptoms

*Adapted from:* Feldman and Gracon (1996)

*Additional Sources:* Dickerson & Atri, 2014; Tampi et al., 2011

Figure 3. Alzheimer's disease natural progression.

Alzheimer's treatment is focused on preservation of cognitive and functional status. It is important to tend to general health care needs such as co-morbidities, preventive health measures, and medication adherence. Rabins and Blass (2014) describe a multi-tiered toolkit for health care providers to address Alzheimer's disease. It has a full therapeutic algorithm using a modern bio-psycho-social approach. They offer guidance in the realms of education, safety, specialty referrals and pharmacological treatment strategies. Essentially, clinicians and caregivers provide direction and advice on issues of safety and security, such as driving and when supervision is necessary. Non-pharmacologic approaches for sleep, nutrition, geriatric syndromes and behavioral problems are framed in a person-centered, individualized problem-solving approach that uses 'define, decode, devise and determine efficacy' approach.

Pharmacologic approaches vary by specialty practice, practitioner and are often limited by the practitioner's biases. Some cognitive agents are used, such as acetylcholinesterase inhibitors and memantine, and mixed medications such as Namzaric®, to delay cognitive decline in persons with dementia. Efficacy of antidepressants used to treat low energy, sadness, and apathy, is mixed; and antipsychotics used to mitigate hallucinations, delusions and agitated behaviors pose a significant risk of cardiovascular harm. The difficulty in prescribing, finding prescribers and identifying the efficacy of medications illustrates the challenges to dementia families and the variations and inconsistencies in the dementia medical model in the U.S.

Meta-analyses of circadian rhythm disturbances and sleep problems do not currently support the effectiveness of any pharmacologic intervention (Rabins & Blass, 2014). However, there is more evolving research on sundowning theory and interventions. There is very limited investigation on melatonin, insomnia and sleep behaviors. There is even less examination about



night psychoses, vivid dreams, and impaired vision (Non-24 and Charles Bonnet Syndrome) as related to dementia.

This quick summary of medicalized treatment is only to persuade the reader that there are very few clinical treatments available to Alzheimer's patients and the brunt of the support, care and advocacy fall to the immediate family. In this dissertation study, that is dementia spouse caregiver.

**Cognitive impairment.** Cognitive symptoms (loss of memory, attention, concentration, problem-solving and praxis) always decline as dementia progresses. Basic screening by primary care providers usually validates caregiver's description of their care-recipients' cognitive domain losses. Families themselves often report disorientation, loss of short-term memory, poor attention, difficulty naming items, and visuospatial losses such as poor depth perception causing falls and getting lost in familiar neighborhoods. They describe an inability to no longer use the television remote control, cell phone and microwave. The social impact is felt by the dyad when attendance at bridge games, movies and hobbies diminishes. A person with dementia often loses their map reading ability, such as the compelling illustration of Henry Fonda getting lost picking strawberries in the movie, *On Golden Pond* (Thompson & Rydell, 2003).

Conversations become difficult with a variety of causes. Anomia and memory loss produce a hesitant, stuttering, repetitive, logorrheic or circumlocutive dialog. Often in mild disease, the care-recipients' conversation becomes one-sided and egocentric. Aphasia, one of the cognitive impairments that is vastly reported in dementia, is the "deterioration of language function" (American Psychological Association DSM 5, 2000, p. 148). Words previously in a person's repertoire become contextual. An individual might name a photo of a spoon, but not be able to finish the phrase "knife, fork, and spoon." In Skinner language, it was found that mands,

the ability to ask for an item without the item present, decreases in dementia, but the tactics, properly identifying an article in context, were stronger (Gross, Fuqua, & Merritt, 2013). This had implication in facilitating and retaining language skills between dyads in the hope of reducing caregiver burden (Watson, Aizawa, Savundranayagam & Orange, 2012).

Williams (2011) reported spouse caregivers were acutely aware of communication deficits originating from the care-recipient. The caregivers described their care-recipients' difficulty understanding complicated explanations, inattention, anomia, repetition, using simple words instead of specifics, using the wrong word, inability to come to the point, switched topics, made up answers or new words, talked but did not make sense. The study sample also identified communication behaviors, for example: does not listen, talked about sex, could not follow direction, heard things backward, talking was harder late in the day, was slow to respond, hardly talked at all, or was silent. The study found the spouses could describe the communication challenges but were less knowledgeable about communication strategies. To address the same issue of lack of knowledge related to dementia communication as well as forgetfulness, Smith et al. (2011) developed a DVD of acted out vignettes of communication challenges and solutions; they are currently incorporating consumer feedback for evaluation, continued development and distribution.

Dementia research has taken elements of cognitive symptomatology, such as amnesia, anosognosia, loss of empathy and apathy and delved deeper into the deficits empirically and experientially. Forgetfulness had the potential to cause fear, embarrassment, anger and low self-esteem for the person with dementia (Ballard, 2010). Although, anosognosia or lack of symptom awareness due to cognitive impairment is not consistent in dementia, persons with dementia often incorrectly minimized and underreported symptoms. They frequently overestimated their

functional capacity (Phinney, Wallhagen & Sands, 2002). Hsieh, Irish, Daveson, Hodges, & Piguet (2013) examined the loss of empathy by a person with dementia. The authors found it was uniquely related to right-sided brain atrophy. The lost empathy emotion had marked effects on burden and spousal relationships.

Brodaty and Burns (2012) described dementia's apathy in terms of epidemiology and management in their systematic review. They reported the nosology of apathy, or passivity, abulia or amotivation, was blurred. They identified the symptom of apathy shared connections and overlapped with cognitive loss and NPS's depression. The apathy subtypes were reported as emotional, cognitive and behavioral. Frequency was reported as high as 92% with the greatest prevalence found in both frontotemporal dementia and severe Alzheimer's disease. Most importantly, the authors associated those specific CI-NPS increased disability for the person with dementia, and additionally caused frustration and poorer quality of life for the caregiver.

The pervasive apathy of Alzheimer's disease discourages spontaneous, dynamic, rapidity and lively give and take dialog. Both executive and conative loss of abilities alters typical life planning, instrumental activities of daily living and are eventually expressed as a startling self-neglect for person, family and life. This foreshadows reciprocal changes in the dyad's RC.

As discussed, typical cognitive losses in Alzheimer's disease affect the dyad in a myriad of ways. As communication disappears and forgetfulness increases, reciprocity is no longer even and sways toward increasing the caregiver's burden. There are changes in ability and less participation in shared activities. Spouse caregivers often become the communicator and translator for care-recipients. Spouses answer important questions related to health history, family dates, names and occasions, and help with making choices. Additionally, Sturm et al. (2011) found even non-verbal communication decreased in a frontotemporal dementia couple

study. In that study, mutual gaze diminished more for FTbv patients (39%) than compared to Alzheimer's disease patients (57%) in their maintained gaze. Their study also supported consistent findings that despite the cognitive decline, social gaze in the early stages of Alzheimer's disease remained intact. Finally, communication breakdown in dementia is stage dependent according to Orange, Van Gennep, Miller, and Johnson (1998). They reported despite the cognitive decline in mild and moderate stage disease dyads were able to achieve overwhelming success in resolving language challenges.

It benefits the readers to imagine a dementia contextual conversation. A comment is repeated twenty time in the space of one hour. There is a need yet again to remind someone to take their daily medicines. Initiating a conversation to make a major life decision is framed in an interaction where your partner has a blunted affect, no eye contact, and no engagement or response. Imagine if your spouse were to recoil from your touch, consider you a sibling, or not know who you are, and all the while share a home, meals, and bedroom. Then you can accurately understand the degree of interpersonal communication loss, social impact and the paralyzed and powerless feelings experienced by dementia caregivers.

**Functional disability.** Functional impairment is a core symptom of Alzheimer's disease, significantly impacting the quality of life of the person with dementia, as well as caregivers. The most accurate indicator of functional impairment is the decline in performance of activities of daily living. Functional scales used to measure instrumental IADL and ADL in geriatric and dementia cohorts identify problem areas for mobility, cognition, and self-care. They also contributed to identifying stage specificity for persons with dementia (Ames, Burns, & O'Brien, 2010; Dickerson & Atri, 2014). In a study by Arrighi, Gélinas, McLaughlin, Buchanan, & Gauthier (2013) it was reported that for each one point change in the MMSE, i.e.: cognitive

decline, a resulting comparative change is reflected in IADL losses in a progressive and hierarchical manner.

There is emerging research identifying the unique relationship between executive dysfunction, NPS and functional status suggesting a common neuropathologic cause. Boyle, Yu, Wilson, Schneider, & Bennett (2013) stated frontal system dysfunction was common and under-recognized among persons with dementia. The symptoms of frontal system dysfunction occurred in early and moderate stages of the disease and were very emotion related with both flatness and hyperactivity. In the study, the symptoms manifested as executive cognitive deficits, such as decreased mental flexibility, higher order thinking, and goal-directedness, and NPS including apathy, irritability, hyper-reactivity, agitation, disinhibition, and anxiety. This executive function and its impairments were shown to be a reliable predictor of lost functionality as described by changes in ADL. The researcher also related the cholinergic deficiency of Alzheimer's disease is particularly severe in frontal brain regions, and this cholinergic deficiency may have significant functional consequences as well as treatment options.

Alzheimer's disease is progressive and persons who have the disease longer, 43% of current cases, need a high level of care, custodial care and long-term care (Brookmeyer, Johnson, Ziegler-Graham, & Arrighi, 2007). The authors reported variability existed in the world's literature on the rate of progression of Alzheimer's disease, which resulted from differences in definitions of severe disease among studies. They reported that 1) six years was the mean time from mild to severe disease, 2) severe dementia stage heralded the patient's need for care equivalent to placement in a health-related facility, and 3) dementia always ended as a terminal hospice disorder. Staging a person with dementia is difficult as there are overlapping periods when physical disability occurs early for some patients and much later for others. There are

many dementia disease staging and functionality grading instruments used, as well as the combination of both. Aditya and Pande (2017) used an OASIS and MRI databases and implemented artificial intelligence via machine learning and data mining techniques to visualize data and classification algorithms for dementia disease staging. The outcomes from using multiple multifactorial data points were encouraging in its detection and quantification of the severity of Alzheimer's disease. It is still in the prototype phase.

The stages of Alzheimer's disease and related dementias are described in many dementia research studies, information websites ([dementiacarecentral.com](http://dementiacarecentral.com)) and self-help books. The use of the staging dictates what type of detailed model or valid instrumentation is used. Empiric research often uses the Global Deterioration Scale for Assessment of Primary Degenerative Dementia (GDS), and as it is also known as the Reisberg Scale (Reisberg, Ferris, de Leon, & Crook, 1988). It provides a seven stage sensitive model that includes symptoms, function, and duration (see Appendix B). Secondly, the Clinical Dementia Rating (CDR) Scale (Morris, 1997) provides a more existential look at dementia in the home environment. The person with suspected dementia, or dementia being measured in serial exams, is evaluated by a health professional in six areas: memory, orientation, judgment and problem solving, community affairs, home, and hobbies, and personal care; one of five possible stages is assigned (see Appendix C). The third scale used in research and clinical practice is Appendix D. the Functional Assessment Staging (FAST) which is related to the GDS (Sclan & Reisberg, 1992). The FAST focuses more on an individual's level of functioning and activities of daily living versus cognitive decline. It is used as a predictive model for determining custodial care needs, prognosticating death and as eligibility criteria for hospice.

For most descriptive research, stages of dementia have been relegated to mild, moderate and severe. The mild stage includes memory problems that are slight but consistent, and there are some difficulties with time and problem-solving. Daily life is only slightly impaired. The moderate stage comprises profound memory loss allowing the person with dementia to retain only highly learned material. They are disoriented with respect to time and sometimes place, lack good judgment and have difficulty handling problems. There is little or no independent function at home. There is a much greater need for reminders. They can usually do simple chores, retain procedural memory, but have few interests. Sometimes incontinence begins with occasional bladder accidents or enuresis.

Severe disease heralds profound memory loss, aphasia, and severe cognitive impairment. Patients are not oriented with respect to time and place and sometimes person. Often there is agnosia, no judgment or problem-solving ability, and they cannot participate in community affairs outside the home without total care and surveillance. They need help with all tasks of daily living and require assistance with personal care for hygiene and continence. Patients become bedbound with 24/7 custodial care and electively enroll in hospice care.

Dementia stages are sometimes streamlined as two dichotomous phases, mild vs. moderate-to-severe. Mild stage preserves some independence, insight and cognitive rehabilitation potential. They can often self-regulate with mild cues and coaching. While moderate to severe stages encompasses ADL loss and the milestones of self-feeding problems and incontinence, there is a severe restriction on autonomy.

Dementia is a life-shortening illness; it is terminal. Predictors of mortality include the degree of frailty, severity of NPS, and biophysical markers of food intake, weight loss, BMI, mobility, and polypharmacy. Other conditions, like sepsis from pneumonia or urinary tract

infection, or co-morbidities such as cardiovascular disease, renal failure, cancer and COPD cause a person's death. However, the functional disabilities due to dementia are major contributors to multiorgan failure, frailty, dysphagia and muscle wasting (Dickerson & Atri, 2014; Rabins & Pearlson, 2009). When autopsies are performed on dementia patients, there are five distinct pathologies that underlie the diagnoses of dementia; they occur either alone or an additive mix. They are Alzheimer's lesions, including neocortical neurofibrillary tangles and neuritic plaques; microvascular infarcts, including micro- and lacunar infarcts; neocortical Lewy bodies; hippocampal sclerosis; and generalized brain atrophy (White, 2009).

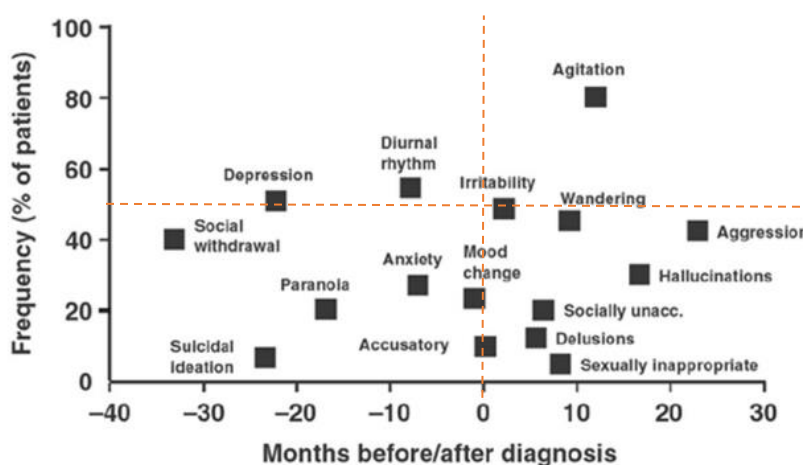
**Neuropsychiatric symptoms.** Neuropsychiatric symptoms above all are significant central features of dementia. They are frequently the most important treatment target (Dickerson & Atri, 2014). However, language and taxonomy can be confusing; the neuropsychiatric symptoms (NPS) are sometimes referred to as behavioral and psychological symptoms of dementia (BPSD) or in general, “dementia behaviors.” This study will use the term NPS, meaning neuropsychiatric symptoms, which one can assess on the Neuropsychiatric Inventory (NPI) (Steinberg et al., 2006). Taxonomy issues aside, we know NPS occur nearly universally in patients with dementia (Lyketsos, 2007; Lyketsos et al., 2002)

The causes for developing CI-NPS have been described and theorized according to disease stage (Jost & Grossberg, 1996; Reisberg et al., 2002), type of dementia or regional central nervous system damage and associated reduced cerebral glucose metabolism (Bozeat, Gregory, Ralph, & Hodges, 2000; Haxby et al., 1990; Steffens, Maytan, Helms, & Plassman, 2005). Distinctive theories are also reported: neurotransmitter-cholinergic deficit theory (Cummings & Back, 1998), a heritable model (Pearlson, Ross, & Lohr, 1990; Tampi et al., 2011), abnormal circadian locomotor activity (Satlin, Volicer, Stopa, & Harper, 1995), a



response to environmental triggers- the Progressively Lowered Stress Threshold model (Smith, Gerdner, Hall, & Buckwalter, 2004) and responses to unmet needs of the person with dementia- the Need-Driven Dementia-Compromised Behavior framework (Algase et al., 1996). It is also evident, that environmental factors related to caregivers (unsophisticated caregiving) and to care-recipients, such as biological and medical stressors (pain, constipation, bladder and respiratory infections), sensory losses (vision, hearing, mobility), and the cognitive decline associated with the disease, contribute to the expression of NPS (Lyketsos, 2007; Lyketsos et al., 2002; Rabins et al., 2006).

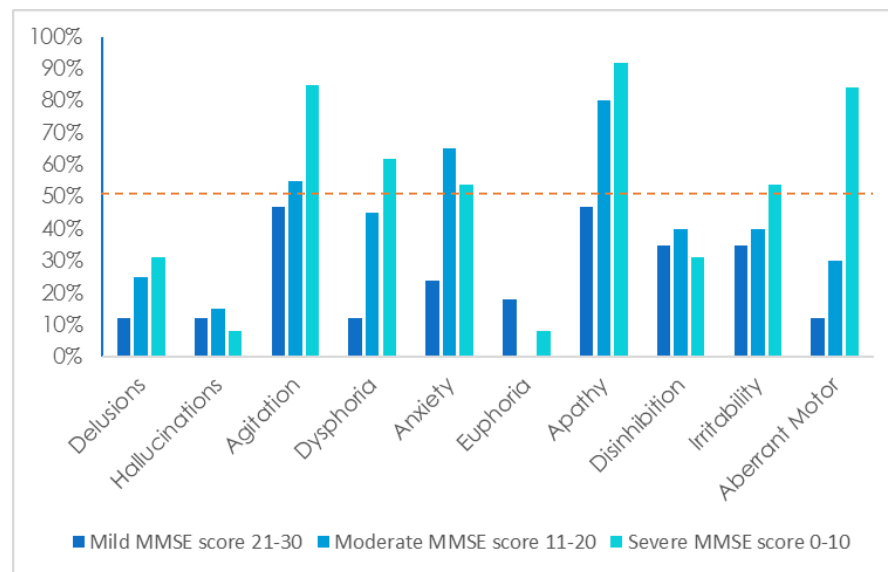
While cognitive and functional ability always declines over time, NPS emerge and fluctuate throughout the disease progression (Tampi et al., 2011). Lyketsos et al. (2002) identified apathy, depression, agitation, irritability and sleep problems as the top five dementia behaviors reported by caregivers. See Figure 4. which describes the emergence of symptoms pre-dementia and two years after the disease onset.



*Reprinted with permission: Jost & Grossberg, 1996*

Figure 4. Time-density plot of neuropsychiatric symptoms.

Neuropsychiatric symptoms can be classified and differentiated according to disease stages. See Figure 5. which identifies common NPS according to MMSE and disease stage.



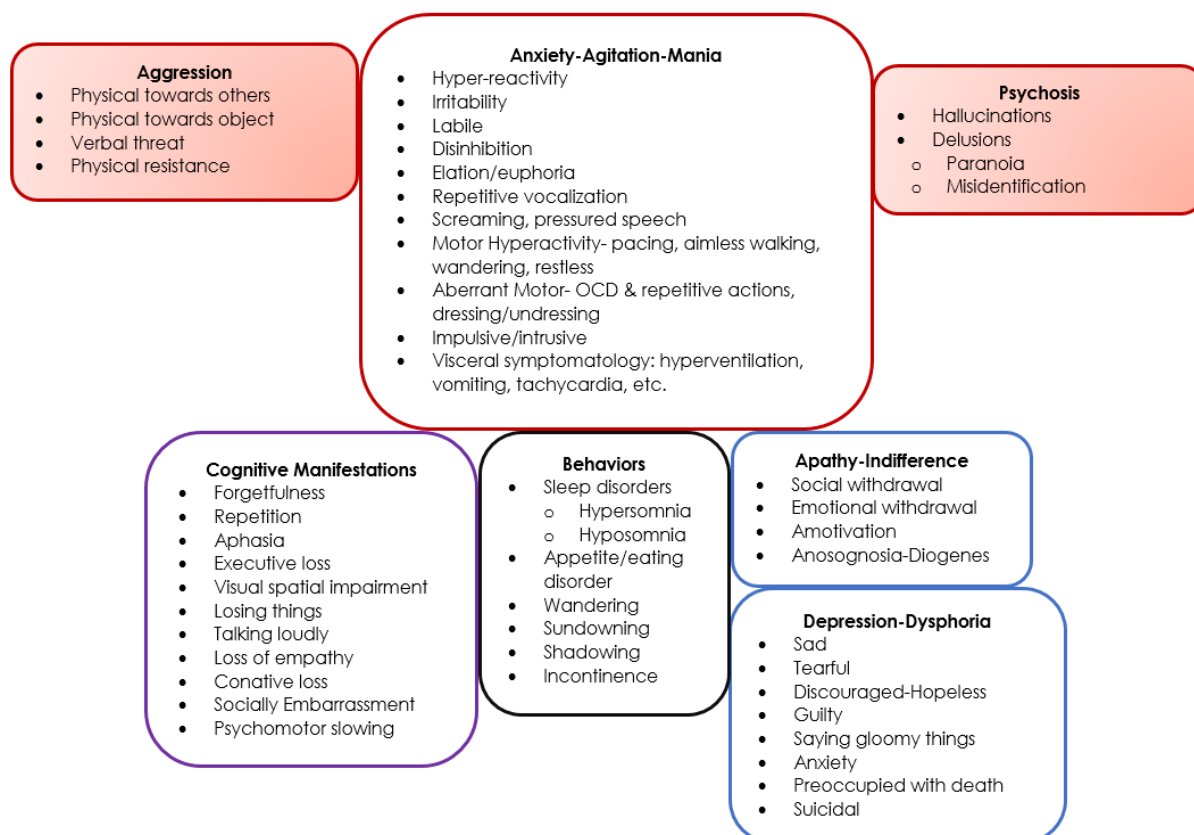
*Reproduced with permission. Mega, Cummings, Fiorello, & Gornbein, 1996*

**Figure 5.** The presence of Behaviors According to Dementia Stages & Mini-Mental Status Exam (MMSE).

Cummings & Back (1998) and Tampi et al. (2011) group symptom clusters: 1) mood disorders (depression, anxiety, and apathy/indifference), 2) psychotic cluster (delusions and hallucinations), 3) aberrant motor behaviors cluster (pacing, wandering, and other purposeless behaviors), and 4) inappropriate behavior cluster (agitation, disinhibition, and euphoria). Behaviors are also divided as aggressive and non-aggressive, as well as physical or vocal expression (Cohen-Mansfield & Golander, 2011). Gaugler et al. (2007) described the impact of constant versus intermittent manifestation of NPS behaviors and suggested there may be acclimatization to chronic symptomatology and outbursts are less tolerated.

Apathy was one of the most reported symptoms of dementia, (Tampi et al., 2011; Brodaty & Burns, 2012) and repetitiveness was highly frustrating to families (Hwang, Tsai, Yang, Liu & Lirng, 2000). Figure 6. represents the author's rendering of cognitive impairment

and neuropsychiatric symptom clusters. It shows the multiplicity and overlap of symptomatology from the easy and tolerable, to the extreme psychosis.



Sources: Dickerson & Atri, 2014; Tampi et al., 2011

Figure 6. Cognitive Impairment and Neuropsychiatric Symptom Clusters.

There are challenges to identify CI-NPS, because they wax and wane, and can be uniquely triggered. The goal is to develop a correct pharmacologic and non-pharmacologic plan for treatment. However, current nosologic studies identify significant issues regarding the classification of symptoms into syndromes and the development of better clinical measures for quantification. Lyketsos (2007) reported that clinically meaningful change in NPS as experienced by the person with dementia and perceived by the caregiver needs to examine relationship elements, burden, disability, quality of life, and resource utilizations. That would be a major reformist development. The NPS needs to be named to identify therapeutic interventions.

### **Conceptual Framework for Dyadic Caregiving and Impact of Dementia on Couples**

The spouse dyad is first established by a legal contract, usually by marriage or a civil union between partners, and often with a significant religious or spiritual testament. A wedding is a public validation of the union, incorporating vows, rights, and responsibilities. As the relationship ages, spousal dyads are constantly confronting and mastering the crises of life, while at the same time developing their shared bond, equilibrating roles, and altering reciprocity. Temporally, marriage is described and measured using anniversaries, milestones, stages and maturity. All marital relationships have a semblance of personality typology and measured degrees of closeness, intimacy, communication (including conflict and emotional expression), expectations, reciprocity, and active interpersonal dynamics. The social currency of couplehood, loss, grief, burden and the emotions of guilt and failure, in the context of dementia spouses, is vital to comprehend as serious challenges for caregivers; it sheds light on their ensuing endurance and perseverance.

**Couplehood.** LoboPrabhu et al. (2005) skillfully depicted the relationship of husbands and wives within the paradigm of socially accepted norms which are then challenged by the adversity of dementia. They concurred that couples must continually confront and master the crises of life, and at the same time maintain their combined bond. No easy task. When dementia was introduced, the fragile balance was thrown into chaos. The authors constructed a framework to explain why couples stayed together and offered practice implications to enable spouses to continue caregiving with sound support. They reported that couples retained togetherness, despite dementia, when the basis of stable marriage included concepts of:

1. quid pro quo (an equal exchange or substitution),
2. values of commitment (respect, pride, and accomplishment despite sacrifice),

3. holding on to the familiar (vs. letting go and abandonment),
4. rupture vs. repair of marital bond (what is the minimal gratification the caregiver requires to sustain the relationship? will a smile or eye recognition suffice?),
5. mastery of separation (decisional capacity and choice migrates from care-recipient to caregiver),
6. spirituality (altruism and prayer),
7. changes in sexuality (loss of shared togetherness) and
8. emotional support (social connections, family support, and kin-care).

**Loss.** Amid failure to thrive at the end stage of Alzheimer's, there is total disconnection for the loved one with dementia from any meaningful communication, commitment or interaction (Burns & Iliffe, 2009). It is a tragic disease that robs a family of their loved one; the caregiving family becomes an intimate observer of the person with dementia's progressive detachment and isolation, and there is a surety of death. This theme has been expressed as disintegration of self (Dempsey, Baago, 1998; Poveda, 2003), intimate or psycho-social death (Garner, 1997; Sweeting & Gilhooly, 1997), living with the dying (Mackenzie & Poulin, 2006), or state of liminality (Kelly, 2008). Dempsey and Baago (1998) suggest three dimensions of loss when explaining latent anguish within dementia dyads. There is the loss of the "person" who has dementia- their critical ability to communicate and express their unique character vanishes. The second dimension of loss is the symbolic loss or psychosocial death. This relates to the personal meaning a caregiver has while witnessing the ongoing, accruing losses of the care-recipient among their social network. It results in a significant restriction of their life plans. It is a loss of their combined hopes, dreams and expectations. Thirdly, the caregiver's personal loss of self or identity, or whom they have become when the burden of caregiving, is increasing and

getting unpredictable. This self-loss becomes cyclical, provoking adaptation and acclimatization; it then results in more dyadic role changes. When there is an inadequate time in the day, due to escalating caregiving needs and role expansion, coping, redefining self and grief-work becomes impossible.

Accruing losses, ever expanding care requirements, and responding spousal role changes caused role captivity, also pejoratively termed "home hostage." The loss included a deficit of the elemental communication exchange, reciprocity, intimacy, and sexuality, which were identified as preeminent components in a marital-spousal-partner dyad (Adams, McClendon, & Smyth, 2008). Evans and Lee (2004) also acknowledged this role change as significant, "the healthy partner may relate more and more to their spouse as a patient; with the potential of a detrimental effect on the mutuality on their relationship" (p.320). The development of behavioral disturbances during the course of worsening dementia (psychosis, anxiety, hypersexuality, hallucinations, incontinence) or side effects of anti-dementia medications (impotence, fatigue, and apathy) also confused marital-spouse roles in the realm of sexuality, or needs for intimacy, affection, self-image or self-pleasure (Newson, 2007). Loss triggers grief.

**Grief.** Grief is defined as an intense sorrow or sadness, especially because of death. In the paradigm of dementia, grief comes prematurely, as physical death is yet to come. Dementia grief included the terms: slow grief (Peterson, 2006), disenfranchised grief (Doka, 2010), anticipatory grief or mourning (Doka, 2005; Rando, 2000) and ambiguous grief (Boss, 2009). Sanders, Ott, Kelber and Noonan (2008) reviewed the pathology of grief, specifically as an initial reaction to the perceptions of loss, and then a direct response to onerous dementia caregiving, i.e.: burden. They specifically tied the two concepts together, allowing the readers to understand that all elements of caregiving evoked some level of grief.

Doka (2005) explained grief as a constant yet hidden companion to Alzheimer's Disease. With dementia, a 'stranger' emerged who needed unceasing care; it was that unique concept that prompted grief, which then became disenfranchised by shame, secrecy or stigma. Sometimes viewed as a premature widow or widower, the dementia caregiver often confronted a cold, non-supportive community. Because he or she was not quite in the accepted bereaved widows' club, the community did not identify the loss, or the grief, and thus devalued it and disenfranchised it. Grief work also seems obstructed by the assumptions of caregiver role and personal burden, heartfelt sadness and longing, and worry and isolation (Frank, 2009, Marwit & Meuser, 2002). There is too much work to be done caring for a person with dementia to tend to self-care principles to understand the nature of grief and therapeutic interventions. Ambiguous grief is the common term, and it was well represented in the literature (Boss, 2009; Boss & Couden, 2002; Dempsey & Baago, 1998; Doka, 2010; Poveda, 2003). It concerned the sense of ambiguity, or the paradox between a care-recipient being physically present and psychologically absent. It seems metaphorical but captures the contradictions of physical living with a nuanced social death. Nancy Reagan called it "the long goodbye."

**Burden.** "Caregiver" is a role identity expression which denotes a broad range of possibilities in the way care is provided. Direct and indirect care are incorporated into daily processes. Time requirements vary depending on degree and availability of outside support, potential day care enrollment, and certainly the extent of safety surveillance required by the loved one with dementia. The average length of time a caregiver possesses that role is 8-10 years (Acton & Wright, 2000; Etters, Goodall, & Harrison, 2008).

The ability of the care-recipient to perform Instrumental Activities of Daily Living (shopping, finances, cooking, traveling, and so forth) and Activities of Daily Living (eating,

bathing, dressing, toileting, and mobility), progressively disappears as the disease progresses. Multi-morbid or chronic health care needs and frailty also play a part in the workload requirements, perhaps tasking caregivers to render nursing or clinical procedures, as well as newly assigned roles of interpreter, chauffeur, surveille-er and financial manager. The reverberating effects of dementia caregiving were the relentlessly high-stress level reported by caregivers to their primary care providers (Fillit, Knopman, Cummings, & Appel, 1999).

In addition to the physicality of delivering care, i.e.: task difficulty and time required, burden takes on multiple definitions in terms of the caregiver who provides the help to a person with dementia. Burden can also be defined in measurements of caregiver self-health, self-efficacy, strain. Additionally, it includes: "measures of the caregiver's coping style, self-esteem, mastery, perceived competence to deal with caregiving tasks at hand, and feelings of being trapped in the caregiver role" (Hansson & Carpenter, 1994; p.55). Bauer, Maddox, Kirk, Burns, and Kuskowski (2001) recognized mastery, or sense of personal control, as a more significant caregiver attribute which influences the ability to endure and shift with experiences as "caregiving is not a static role" (p. 329). The essential premise of burden is that the needs of the patient and caregiver are fluctuating, and require caregiver skills to adapt both in mastery and personality characteristic, thus accounting for individual differences in caregiving outcome (Helves, Green, & Almeida, 2005).

Molloy, Bédard, Pedlar, & Lever (1999) and Smith, O'Brien, Ivnik, Kikmen, & Tangalos (2001) reported two successful options that would indeed provide high value to the care-recipient: 1) reduction of caregiver burden and 2) increased caregiver quality of life. The authors suggested adjusting those two criteria would lead to decreased nursing home placement. There is a gap in literature and research that could further explain the caregiver's RC and relationship role



change when their life-partner is diagnosed with dementia. It is always presumed that the healthy spouse's role expands, and will expand, to fill the need.

Perhaps the most burdensome of all caregiving tasks is that of safety, surveillance or the ever-watchful eye. Dementia patients desire to be with their caregiver all the time. It is called shadowing. Persons with dementia relish the comfort, recognition, and familiarity of known and familiar environments. Dementia patients have no notion of time passage; they are on their own biorhythmic clock. This regular contact day in and day out is wholly exhausting as described by a participant in a qualitative research study, "I wasn't getting my sleep. It was difficult to sleep because you were listening all the time" (Ryan & Scullion, 2000, p.1191). Caregiving becomes more intense as cognition and functionality fail, and caregivers specifically worry about the care-recipient as being vulnerable, to injury and accident and stigmatized or disrespected. The safety issue surfaced as a mechanism of vulnerability in the Butcher, Holkup, & Buckwalter's study of 30 caregivers (2001). They noted in results, "[dementia] family members were vulnerable to strangers. As a result of these worries, caregivers kept up a vigilance that became physically and emotionally draining as their loved one's mental condition deteriorated" (p.475). Within the realm of mastery and burden, it is a natural conclusion that caregivers have been dealt an enormous task to integrate caregiving in their already-full-life of personal growth and milestones (Erikson, 1963). When the everyday challenges of the aging adult are coupled with enormous caregiving duties, it then becomes a certain test of endurance.

Caregiver burden is a striking construct when placed in the paradigm of marriage, which thrives on notions of commitment, vows, obligations, and debts. Add the concepts of loss and grief to that fragile balance, and you can envision the complexity and difficulty required to maintain the marriage, partnership, and dyad while facing dementia disease.

**Guilt and Failure.** Dementia exposure also contributed significant emotional tolls on caregivers, ranging from distress, guilt, negative thoughts, weariness, anger/impatience and worry (Samuelsson, Annerstedt, Elmstahl, Samuelsson, & Grafstrom, 2001). Failure and guilt were omnipresent throughout the studies. Caregivers were tasked with superhuman roles and assignments. The weight of the world seemed to lie on their shoulders with frequent thoughts of not wanting to burden others. The emotional rollercoaster is an apt description.

Armstrong (2000) found that caregiver wellbeing was a theme which encompassed pressures and obligations, the changing relationship and the psychological welfare of the caregiver. Participant caregivers reported problems with their own mental health. For example, a participant recalled, “I did feel ill, my hair was coming out. I was very tearful, anything would set me off” (Armstrong, 2000, p.36). Caregivers report guilt, helplessness, loss, loneliness and regret. Characterized as a type of emotional challenge, caregivers often felt torn between a personal emotional exhaustion and convictions that outside help, adult day service use, and institutionalization are signs of personal failure and the fracture of vows and marital promises (Paun & Farran, 2006).

When the physical drama of institutionalizations plays out in dementia families, it often symbolizes guilt and failure to the extreme. Transfer to long-term care for custodial needs or unremitting CI-NPS and behaviors is heart wrenchingly sad. Ryan & Scullion (2000) described a crying caregiver’s statement, “...you feel so guilty that you were so inadequate ... that [he] has to be put into ... care. The guilt is so terrible, and it doesn’t get any easier” (p.1192). Other participants in the same study related their feeling about nursing homes as: awful, bad, terrible, sad and miserable. Crying was noted time and again.

In Gaugler et al. (2009) systematic review of predictors for nursing admission for dementia patients, the authors reported severe cognitive impairment, loss of ADL, behavioral symptoms and depression as the most frequent patient triggers cited. Caregivers who had more emotional stress, a desire to institutionalize the person with dementia and possessed the feeling of being “trapped” were more likely to actively seek nursing home admission for the care-recipient.

The defining moment, or the flash of recognition when a caregiver realized the impossibility of continuing primary home care of their loved one with dementia, is a genuinely sad moment. That crisis, or a catastrophic precipitating event, is recognized in many caregiving and institutionalization of persons with dementia articles. Armstrong (2000) identified the challenges of caring, which included physical problems, personal care, challenging behavior, and communication issues. The author noted that wandering, aggression, incontinence and physical dependency contributed to the consideration of care placement. In her study, she cited a caregiver comment, “I think the incontinence is probably the worst thing, she didn’t have any control over her bowels” (p.35). Another stated, “I couldn’t lift him anymore. I couldn’t manage on my own” (p.35). The inability to provide care, or the distinct limitation of care because of escalating patient needs, was reinforced by a study of 29 caregivers (Strang, Koop, Dupuis-Blanchard, Nordstrom, & Thompson, 2006). Crisis as an initiator and looming future calamities were key concepts. The authors proposed there was a dread that the patient’s health status would require an ever-increasing care demand with a potential for devastating deterioration. One of the study’s participants described this, “I don’t know how much longer I can keep this up on my own” and “it’s getting to be too much” (p.33). Similarly, Butcher et al. (2001) reported the qualitative study theme, *moving toward the unavoidable decision*, characterized by thoughts that

it is becoming unmanageable and reaching a breaking point. The spouse caregiver is also aging and may have their own frailties, disabilities and health morbidities.

**Transcendence.** Self-transcendence was described by Benner (1989) as the nexus of a spiritual experience. It pulled caregivers out and beyond themselves to a higher being. Self-transcendence was also been compared to the self-realization that is foundationally human and the unique source of authentic spiritual existence that results in human's longing for life's meaning and satisfaction (Acton & Wright, 2000). The nature of being a dementia caregiver provokes introspection and imaginable despair, but the literature suggests the experience of dementia caregiving in itself, provides positive opportunities for growth and development. There is no question that the role of dementia spouse caregiver is a critical life event.

Most caregiving research, per Gaugler et al. (2007) focused on the negative aspects of providing care to dementia patients and the significant toll it took on the caregiver; but there was resilience, or the "ability of certain caregivers to persevere in at-home caregiving roles" (p.38). Gilley, McCann, Bienias, & Evans (2005) found that even though there was an emotional cost, there was an ability by caregivers to adjust psychologically to endure, and it was measured in both positive dimensions of action and positive caregiver affect. Leblanc, Driscoll, and Pearlin (2004) studied religiosity as a moderating and uplifting concept within the context of caregivers to dementia patients. They proposed it was a moderator of emotion with an ability to temper stress and decrease caregiver depression. Tarlow, Wisniewski, Belle, Rubert, Ory, & Thompson, (2004) reported Alzheimer's caregivers believed their caregiving satisfied personal needs of usefulness, supported an appreciation of life, helped develop a positive attitude and ultimately strengthened personal relationships.

The assignment of dementia spouse caregiver role encompasses burden, loss, and grief, feeling of guilt and failure, and finally comes full circle; then transcendence is facilitated in some way. Newman (1986) contended the result of that transcendence was love, uniquely important in this research study and vital to the present study's married dyads.

It is advantageous to break down the requirements unique to dementia disease to understand the psychometrics of caregiving. "Caregiving demands and related psychological distress are driven primarily by the needs of the care recipient..." (Pinquart & Sörensen, p.8, 2011). The dementia caregiver is faced with a triad of challenges by the person with dementia: functional loss, cognitive impairment, and the potential development of neuropsychiatric symptoms of dementia. First, caregiver and care-recipient roles alter to accommodate a change in the instrumental activities of daily living. There are increasing custodial care requirements as the activities of daily living recede. The number of hours, physicality, and intensity of caregiving increases. Secondly, cognitive impairment alters reciprocity, communication and the cerebral benefits of interpersonal sharing. Meta-cognition and conative abilities diminish. Finally, thirty percent of community-dwelling and eighty percent of persons with dementia in a residential home had co-existing CI-NPS (Tampi et al., 2011). This can be a tedious, frightening or vexing issue realized by both caregiver and care-recipient. Understanding dementia caregivers require the reader to understand relationship closeness, dementia, functional/physical deterioration and disease progression, and dementia symptomatology of cognitive loss and advent of neuropsychiatric symptoms. There are direct, reciprocal and cumulative influences on the caregiving paradigm.

## **Review of Scientific Literature**

After a scoping exercise, the author found published quantitative and qualitative studies examining the relationship of spousal caregiver RC and its links to dementia CI-NPS were limited. Few research studies matched both RC and CI-NPS with caregiving outcomes or suggested reflective changes in RC or variation of CI-NPS. Most investigations loosely discussed the caregiver's relationship in a disattached manner or as broadly associated findings. The most current systematic and integrative literature reviews, meta-syntheses and Cochrane database with inclusion criteria of dementia caregivers and relationship quality were queried for the author's study. The investigator found four studies. However, cognitive impairment elements and neuropsychological symptoms did not always appear as hypothesized variables in the reviewed articles, but since the findings were so clinically meaningful, they were deemed ripe for discussion. Some of the examination of dementia symptomatology findings, caregiving outcomes, and RC effects were a serendipitous finding.

Ablitt, Jones, and Muers (2009) reported overall evidence linking the quality of the caregiver and care-recipient relationship to their overall experience of dementia, citing lower prior relationship quality was related to caregiver's outcomes of depression, burden, and emotional reactivity. Likewise, the literature review by Quinn et al. (2009) suggested pre-caregiving and present relationship quality had an impact on the caregiver's well-being. Also, they found that the level of 'behavioral problems' influenced the caregiver's perceptions of relationship quality. Qualitative meta-syntheses discovered trends concerning the impact of dementia and they resulted in transitions and loss. Although neuropsychiatric symptoms were not overtly identified, one study recorded that dementia symptoms provoked hyper-reactivity by the caregiver and functional loss was commented on in another study (Evans & Lee, 2014). The

experience of living with a person with dementia was described as themes of loss, change, crisis, adjustment and moving forward (Pozzebon, Douglas & Ames, 2016). Again, the authors did not specifically address CI-NPS, but some persuasive elements of RC related to dementia were discussed in their findings. The authors reported the ‘Loss of Partner’ theme revolved around spouses’ perceptions of change in the very foundations of their dyadic interaction. The study also recognized loss and change in the 1) spouses’ perceived quality of the relationship, 2) feeling that their partner had become a different person, 3) couples’ reduced reciprocity and connectedness, 4) interpersonal communication, and 4) variations in sexual intimacy (as found in Pozzebon et al., 2016, p. 542).

**Empiric studies.** Limited published studies looked at a spouse caregiver sample and demographics of the dementia partner. Some authors chose disease typology and one element or a composite score of RC concepts (see Appendix A). They used the RC elements either as a variable or a descriptive demographic and proposed to find relationships with one or a few or a composite score of items of CI-NPS (see Figure 6). The authors most frequently reported findings that reflected 1) caregiver outcomes (health, coping, and so forth.), 2) care-recipient outcomes (quality of life, prognosis, and so forth), 3) altered RC (better or worse), 4) altered CI-NPS (better or worse) and 5) global caregiving outcomes (mortality/morbidity, institutionalization, and so forth).

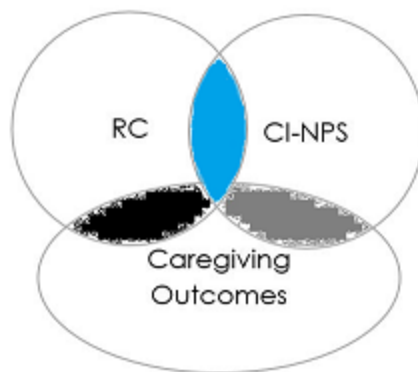
Primarily, relationship closeness and NPS were frequently measured variables, but not always correlated or explained in discussion sections. Cognitive impairment elements, especially communication have been studied independently in the dementia population, but only in a limited way within the context of dementia spouse RC. It is important to note for the readers; there is a very gray and overlapping description of both relationship closeness elements and CI-

NPS. For example, apathy operationalized as poor decision making or inability to care to make decisions can be categorized as an executive loss in the care-recipient's cognitive impairment. It is also measured as a neuropsychiatric symptom under the heading of depression. Thirdly apathy restricts RC and the ability to portray RC elements of communication, affective emotion, and conflict resolution. It is a complicated paradigm.

In addition to the author's unpublished integrative review (Schjaveland, 2015), the author searched recent articles from 2014 to 2016. The review comprised reported findings in married couples that specifically looked at all quantitative studies employing instruments measuring RC and CI-NPS of dementia. Ten studies found and described a complex relationship or bidirectional link between the relationship closeness of the dyad, dementia CI-NPS, and other caregiving or caregiver morbidity variables.

The following Figure 7. illustrates the complexity of research in this field of study. The symmetric differences of the three sets (white area) are the typical independent study variable applications with countless subsequent studies, findings, and discussion. The intersecting study aims and variables result in narrowed findings and limited generalizability. To control data, this study is concerned with the overlapping areas on the Venn diagram of RC, CI-NPS, and caregiving, including the 3-set intersection (blue area). This review of scientific studies is organized into three sections: relationship closeness' influence on CI-NPS, cognitive impairment and neuropsychiatric symptoms' effects on RC, and RC and CI-NPS' mutual relationship to caregiving outcomes.





Relationship Closeness (RC)

Cognitive impairment and Neuropsychiatric Symptoms (CI-NPS)

*Figure 7. Study variables with relation to relationship closeness, cognitive impairment and neuropsychiatric symptoms and caregiving outcome findings.*

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***Relationship closeness vs. cognitive impairment and neuropsychiatric symptoms.***

Despite the scarcity of investigations, relationship closeness was found to have a significant connection with dementia behaviors. Studies reported that pre-dementia and present relationship closeness were related to 1) changes in NPS, 2) the caregiver's perception of dementia behaviors, 3) the caregiver's reactivity to NPS, and 4) the opportunity for the caregiver relationship closeness' to influence the home management of the dementia symptomatology. Some studies then reported further reciprocally altered care-recipient CI-NPS, whether mitigating the behavior or exacerbating it.

In reviewing the literature, seven studies analyzed, emphasized and discussed a direct link between relationship closeness and its correlation with the presence and degree of CI-NPS. Gibbons et al. (2014), reported when the caregiver had a poor pre-dementia RC, there was a tendency to report more CI-NPS. They suggested a poor premorbid RC may even mediate aggressive behaviors displayed by the person with dementia. Similarly, Perren, Schmid, Herrmann, & Wettstein (2007) found a negative attachment style of the caregiver, specifically

the avoidance of closeness, was related to a higher level of observed CI-NPS. Norton et al. (2012) examined a large quantity of secondary data from the Cache County Dementia Progression Study. They reported no significant correlation between RC and neuropsychiatric symptoms but did find that a good premorbid spouse caregiver relationship closeness predicted a slower neurocognitive loss and functional decline. It slowed the progression of Alzheimer's disease.

Burgener and Twigg (2002) identified a 'good' or high RC and described the improvement in the care-recipient's conative skills. For example, they reported the higher, or better RC was, related to an improved spouse with dementia's problem-solving, task performance and social behavior. Likewise, Lawrence et al. (1998), and Morris et al. (1988) reported caregivers who had higher RC and who were more intimate with their spouse care-recipient, reported a negative correlation between RC and NPS scores. Caregivers with high premorbid RC also had lower scores for reaction to NPS. Conversely, caregivers with low pre-dementia RC reported greater response to disturbing behaviors, which then associated a strained communication pattern with the person with dementia (Steadman, Tremont & Davis, 2007).

***Cognitive impairment and neuropsychiatric symptoms vs. relationship closeness.*** Three studies (de Vugt et al., 2003; Hsieh et al., 2013; Riedijk et al., 2008) looked at the relationship between CI-NPS of aphasia, apathy, and empathy, and the spouse caregiver's perception of their relationship closeness to their partner with dementia. All three studies agreed that aphasia and apathy accounted for alterations in relationship closeness. The care-recipient's poor communication, passivity, lethargy, apathy, and indifference influenced a substantial change in dyad closeness, mutuality, reciprocity, and shared activities. De Vugt et al. (2003) in a Netherlands study, found communication problems due to a dementia patient's lack of

spontaneous speech and incapacity to respond, hindered the sharing of meaningful thoughts and feelings. The communication loss in turn, affected the reciprocity of the relationship as viewed by the spouse caregivers. The authors also reported apathy, apart from any other symptom clusters of hyperactivity and psychosis, was a significant predictor of the spouse caregiver's negative relationship closeness. The poor relationship quality was described as the spouse caregiver's feelings of being rejected, dismissed and alienated.

An Australian study by Hsieh et al. (2013) and the Netherlands research by Riedijk et al. (2008), both looked at frontotemporal dementia which has the potential for very severe CI-NPS. The dementia symptomatology included: aphasia, disinhibition, executive dysfunction, impairment in the regulation of personal conduct, loss of insight and emotional blunting. Both investigators concurred that a loss in communication (aphasia) and the uniquely different CI-NPS of apathy, had a significant negative relationship with the caregiver's relationship closeness. Hsieh et al. (2013) found in post hoc analysis that caregivers reported an overall less caring feeling and relationship quality toward their spouse with frontal symptoms of dementia. Riedijk et al. (2008) reported significant findings ( $p > 0.001$ ) in which caregivers rated their relationship closeness elements of nearness, communication, mutual viewpoint, and getting along had declined since dementia diagnosis. They attributed an RC loss to frontal lobe behaviors and linked the personality blunting (low energy, apathy, hypomimia and abulia) with that domain's cerebral disease. Hsieh et al. (2013) also found 100% of the spouse caregiver sample reported apathy as a CI-NPS which their spouse with dementia expressed daily.

The limitations of the studies (de Vugt et al., 2003; Hsieh et al., 2013; Riedijk et al., 2008) warrant cautious interpretation and generalizability of results. Small sample sizes (46-63), restricted dementia types (Fronto-Temporal vs. Alzheimer's), relatively young age of participant

and participant attrition were reported and discussed by authors; power analysis for sample size was not recorded in the studies, but samples were identified as “in keeping with previous studies.” However, these valuable studies contribute to foundational work exploring the relationship between CI-NPS, relationship closeness symptoms and the proclivity of apathy.

***Relationship closeness, cognitive impairment and neuropsychiatric symptoms vs. caregiving outcomes.*** Thirteen studies that measured RC and CI-NPS, were focused on measured caregiver outcomes. They were not able to determine causality, but essentially found that poor RC in the presence of CI-NPS produced negatively correlated, or poorer spouse caregiving outcomes and morbidity. Good RC in the presence of dementia symptomatology positively related to better-quality caregiving outcomes. Limitations of the studies were recognized, there was little discussion of the social impact and measures of RC, and relationship closeness was sometimes not scientifically measured or analyzed. See Table 2. for a summary of caregiver outcomes related to RC and cognitive impairment and neuropsychiatric symptoms. The three-way relationship is discussed further.

Table 2.

***Studies Finding Negative Correlations/Poor Caregiver Outcomes Related to the Cognitive Impairment and Neuropsychiatric Symptoms and Relationship Closeness***

| Measured Caregiver Outcome                    | Authors   |
|---|---|
| Burden  | Gibbons et al., 2014<br>Hsieh, Irish, Daveson, Hodges, & Piguet, 2013<br>Rankin, Haut, & Keefover, 2001<br>Riedijk et al., 2013<br>Steadman et al., 2005) |
| Depression, adverse emotions or affect change | Burgener & Twigg, 2002<br>Fauth et al., 2012<br>Gibbons et al., 2014<br>Morris, Morris, & Gibbons 1988  |

|                                |   |
|--------------------------------|---|
|                                | Rankin et al., 2001   |
| Role captivity and strain      | Burgener & Twigg, 2002<br>Gibbons et al., 2014<br>Kramer, 1993<br>Morris et al., 1988                                       |
| Well-being and quality of life | Burgener & Twigg, 2002<br>Gibbons et al., 2014<br>Kramer, 1993<br>Perren, Schmid, & Wettstein, 2007<br>Riedijk et al., 2013 |
| Use of home health resources   | Roelands et al. (2008)  |
| Decision to institutionalize   | Spitznagel, Tremont, Davis, & Foster; 2006<br>Winter, Gitlin, & Dennis, 2011  |

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Overall higher relationship closeness, whether ‘good’ pre-dementia RC, or greater than average ‘current’ RC, was found to be related to better caregiver outcomes in terms of depression, and physical and mental health (Burgener & Twigg, 2002; Fauth et al., 2012; Gibbons et al., 2014; Rankin, Haut & Keefover, 2001; Steadman et al., 2007). Rankin et al. (2001) looked first at caregiver outcomes and reported that overall marriage satisfaction and cohesion was significantly higher in caregivers who did not have depression. Steadman et al. (2005) found an inverse relationship with premorbid relationship closeness and caregiver burden. Also, Kramer (1993) concluded that ‘close’ dyads with good prior-to-dementia RC scores were related to lower caregiver depression, improved marital satisfaction, and better caregiver quality of life.

Six studies reported higher RC related to better caregiver health, but those positive results were not consistent. For example, Morris et al. (1988) found that pre-dementia and post-dementia intimacy was inversely related to caregiver strain and depression. This suggests if a

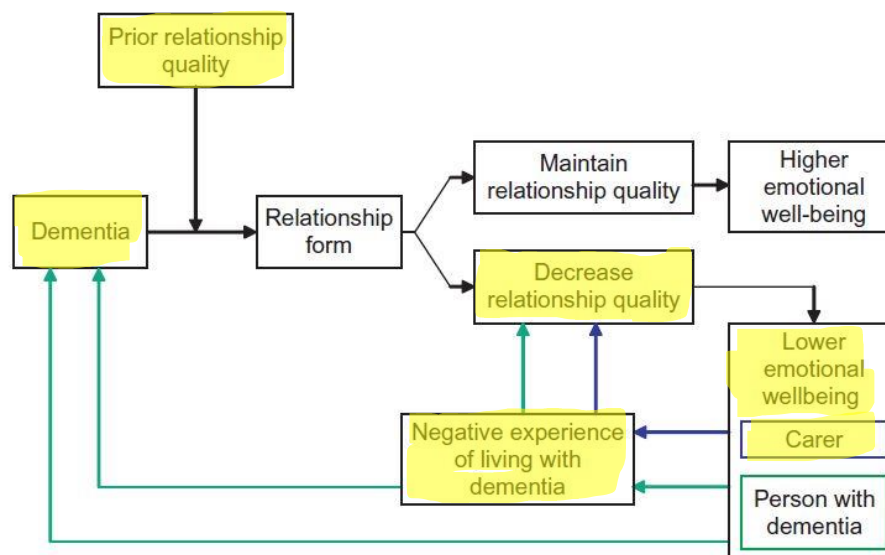
spouse caregiver had a very close, ardent and devoted relationship, likely many years long and shared a close 24/7 lifestyle, the caregiver would feel the dementia loss viscerally and soulfully, thus increasing their strain, grief, and depression.

Hsieh et al. (2013) suggested that the loss of RC and acute CI-NPS of frontal behavioral variant dementia are different and more pronounced when compared to Alzheimer's disease and frontal dementia with progressive semantic aphasia. Alzheimer's caregivers were less able to tolerate emotionally reactive care-recipients and had a decreased RC and moderate burden. While behavioral variant caregivers were faced with care-recipients who were flat, unemotional and lacked empathy; those caregivers had a much poorer RC. Finally, semantic variant dementias triggered a loss in RC, but because of the severe language loss, the caregivers felt more burdened than the other two dementia type cohorts.

Some unusual and complicated relationships between variables were identified. Fauth et al. (2012) reported a novel finding that relationship closeness was related to better caregiver outcomes when discussed cross-sectionally, but worse in prospective measures. This suggested there may be time points during the disease when RC ebbs and CI-NPS and functional loss may be at a climax. Likewise, caregiver outcome findings by Riedijk et al., (2013) were reported as a balancing act when NPS were stable, there was improved communication and sharing between the dementia couple, and there was a related decrease in caregiver outcomes, the burden was less and psychological well-being was stable. Finally, the study by Perren et al. (2007) discussed that caregivers' attachment style of avoidance and anxiety in the face of high-level CI-NPS, was related to caregiver's decreased scores in well-being. These studies all suggest a temporal nature to the disease and symptomatology as well as variable reactions by caregivers.

Findings were also reported for a spouse caregiver's desire to institutionalize, dementia researchers' term for a care-recipient transferring living environment from home to a facility, or, more succinctly, admission for custodial care in community living. These facilities are referred to as a nursing home, long-term care or simply, care home. An inverse correlation of the quality of pre-dementia relationship closeness and severe CI-NPS was a predictor for male spouse caregiver's desire to institutionalize (Winter, Gitlin, & Dennis., 2011). Investigators also recognized a high general family functionality (other family contacts, respite, resources, and social support) was found to be more significant than the caregiver's RC in the group found to have no desire to institutionalize (Spitznagel, Tremont, Davis & Foster, 2006). In another study, Roelands, Van Oost, & Depoorter (2008) found no relationship between the quality of present RC and CI-NPS as a predictor for the use of support services. Co-residence, a positive attitude towards external resource and increased problem solving predicted more service usage (nurse, home care, house cleaning, social services, or day care). However, those not using resources reported a better quality relationship outcome by personally engaging in the care. This suggested spouse caregivers did not rely on outside care because of good or bad relationship closeness, nor did they seek paid care when their spouse with dementia had behavioral spikes. They either liked or disliked paid care in lieu of the degree of RC, CI-NPS and burden.

To illustrate the inter-relatedness of the dyad, RC and dementia disease, Ablett et al., (2009) proposed a theoretical model that describe those links. In this model, Figure 8., when a person develops dementia, and a family member assumes the role of caregiver (carer), the quality of the prior relationship will determine the form that the relationship takes, and how it will manage in the future, all in the context of dementia disease and symptomatology.



Reproduced with permission Ablitt et al., (2009)

Figure 8. The theoretical framework for well-being and relationships in dementia.

**Qualitative studies.** Too few published qualitative studies report thematic results that described the link between the care-recipient CI-NPS and the spouse caregiver's relationship closeness. Lindauer and Harvath (2014) published the most recent meta-ethnography about the meanings caregivers give to dementia-related changes in care-recipients. In a mixed caregiver population of spouses and adult children, they synthesized findings from 31 articles identifying metaphors, connections, and discrepancies. Overall, participants described the personal meaning of dementia-related changes for themselves as caregivers to be a *loss*, *role change*, and *stigma*. Some participants also identified positive meanings of dementia-related changes: *opportunity to care* (give back), the *opportunity for power* (independence in decision making) and *opportunity for personal growth* (learning new skills). However, again the experiences and subjectivity of the phenomenological approach denied an empiric recognition of dementia symptomatology.



Two qualitative research studies from the US, Boylestein and Hayes (2012), using a modified grounded theory approach, and Harris, Adams, Zubatsky, and White (2011), using interpretive phenomenology, found relationship closeness was negatively altered in response to dementia CI-NPS. The authors in both studies identified current relationship closeness was strongly related to the couple's premorbid relationship closeness, which included a historical accounting of cooperation, emotional and intellectual support, shared activities, roles, and affection. They also reported poor elements of RC, such as a history of abuse, low income, and health crises affected the current dementia experience. Lower perception or poor relationship closeness influenced neuropsychiatric symptoms negatively. It was noted in comments such as, "... if somebody that doesn't love him is in charge [of his care] ...he deteriorates awfully bad...[like]when I'm gone" (Boylestein & Hayes, 2012, p. 595-6). Boylestein and Hayes (2012) reported two affected themes. The *no one in there* theme was a disruption code in their analysis of marital closeness, and the global care-recipient losses proved *maintaining social activities* was a barrier to a marriage reconstruction code. This suggested the CI-NPS affecting communication, mutuality, and interdependence were recognized not as a symptom *per se*, but as a consequential care-recipient behavior experienced by spouse caregivers.

Harris et al. (2011) described the inability of the care-recipient to make decisions, and their severe loss of interest and apathy, contributed to poorer marital relationship quality as interpreted in the findings and discussions. Hellström, Nolan, and Lundh (2007) as well, recorded the results of care-recipient inaction, flatness, unresponsiveness, likely the CI-NPS of apathy. The study caregiver participant stated, "...nevertheless we are lonely in a way. I do my things ... and she is in here pottering. Staring at TV mostly sits down sleeping. You live in two small worlds. You have a common world and then you have your own world besides too" (p.

402-3). These studies again reinforced the loss of personhood and conative abilities, plus the dimension of apathy significantly alters how caregivers experience their life with a dementia spouse care-recipient. The three studies conversationally described CI-NPS as the care recipient's lack of memory and communication, loss of instrumental and activities of daily living, apathy, confusion, egocentricity, and angry or sad moods. Themes specifically describing CI-NPS effects did not emerge from studies.

The qualitative studies just discussed had unexpected findings. They identified that somehow an overall improved relationship closeness, resilience or perseverance along the dementia course occurred, much like the quantitative studies of Burgener and Twigg (2002) and Gibbons et al., (2014). By some means, a warmer, closer and accepting marital relationship was described in the dialogal interviews and thematic interpretation. Additionally, the Swedish study by Hellström et al. (2007) described a verbalized commitment and desire to work hard to sustain or reconstruct the marriage in a global affectionate, appreciative and loving manner; and those positive feelings persisted through the dementia disease, neurocognitive losses, and progression of psychiatric symptoms. This suggested a pro-active caregiver is acclimatizing to a relationship and co-constructing the new "we" within the dementia disease experience. Moreover, it reinforced the breach in authentic measurement of relationship closeness according to instruments; there is a yet undescribed exceptional closeness that is briefly captured by qualitative but not quantitative studies.

Synthesizing data, descriptions, results and findings, and information from the above-discussed studies, summarily described an altered relationship closeness in response to the challenge by dementia symptomatology. A conceptual framework that illustrates the essential components is offered by the author (figure 9). This model used the lens of relationship

closeness. It magnifies the couple's personality as a central theme to the caregiving paradigm. As discussed, the married couple has a baseline level of relationship closeness. Both caregiver and care recipient view each other as interactive partners, incorporating the marriage history, intimacy, and bond. It encompasses all of the personhood, resilience, and interdependence concepts, as well as communal living. The model weaves the primary focus of relationship closeness with competing influences (dementia disease, CI-NPS and external variables) and processes of burden (Novak, & Guest, 1989) and coping (Vitaliano, Russo, Carr, Maiuro, & Becker, 1985) with consequential caregiving outcomes. The lens of relationship closeness would become blurred in some places (lesser, poor or negatively changed RC) and clear in others (greater, healthier or changed for the better RC). It is that blurring, that lack of knowledge about how dementia spouse caregivers narrate, describe and define their relationship closeness with their spouse care-recipient in the presence of dementia and all of its elements, that again raises as an unknown, poorly described, and less investigated gap in current research.

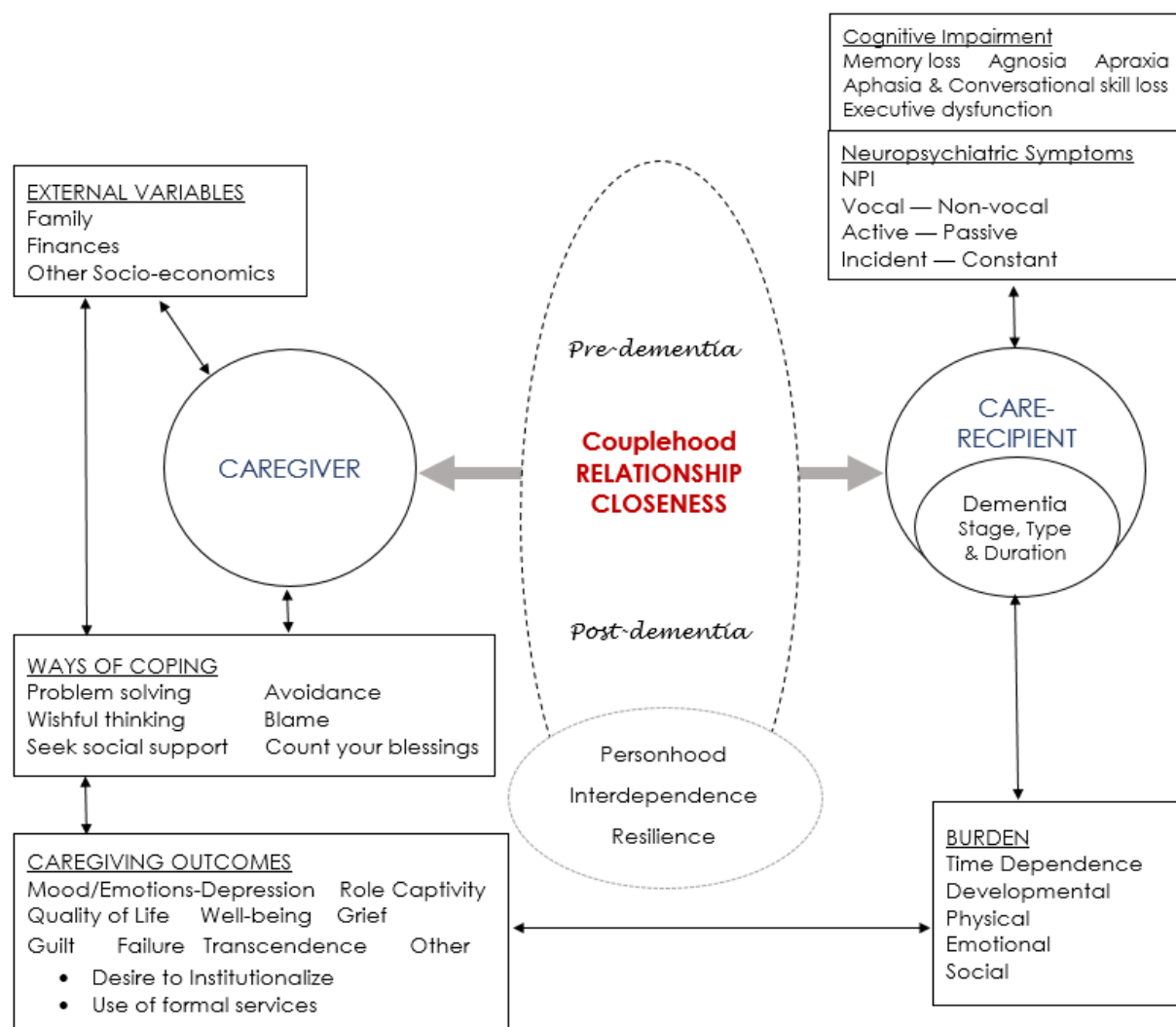


Figure 9. Theoretical Model for Relationship Closeness and Dementia Spouse Caregiving

## Summary

This chapter has introduced a depth and complexity to dementia care dyads, relationship closeness and the current state of science exploring those interactions and the spouse caregiving phenomenon. The overarching construct of relationship closeness is the most important parameter to be considered while analyzing how the spouse dyad responds to CI-NPS, and how relationship closeness changes when the couple is faced with dementia. Hence, relationship closeness is a prominent factor to investigate early in dyadic caregiving (Motenko, 1989; Wright,

1991). Regrettably, the couple's "together life biography" and pre-dementia relationship closeness are greatly underestimated in clinical practice (Davies & Gregory, 2007).

Pre-dementia relationship closeness and current relationship closeness colors the way a spouse caregiver makes decisions and renders effective and nurturing care, or not. It triggers advocacy or ambivalence. It is also known that a spouse's vows, vigilance, worry and tireless caregiving result in incredible morbidity. Moreover, empiric literature has shown relationships characterized by kindness, respect, and warmth, or less criticism, conflict, and family dysfunction are associated with better caregiver and care-recipient morbidity and caregiving outcomes. Additionally, the care-recipient behavior is a significant controlling factor for the caregiver's reciprocal emotions, relationship, burden, and depression. Therefore, caregivers would be in better states of health and wellness if clinicians were aware of the dyad's ability to communicate, the efficacy of their interactions, the strengths, and weaknesses activated by dementia disease and the vulnerabilities now present in the dementia dyad's life together experience.

The next chapter describes the existential philosophy and phenomenological method of the author's research study: the phenomenon of a dementia spouse caregiver's relationship closeness in the presence of dementia disease.

*There is only one thing a philosopher can be relied upon to do,  
and that is to contradict other philosophers.*

*William James (1842-1910) a pioneer Physician, Psychologist, and Philosopher*

### **Chapter Three: Method of Inquiry**

This chapter introduces qualitative nursing research and presents the philosophical underpinnings that steer this phenomenological study. Roots of philosophy, origins of phenomenology and the U.S. mid-century modern philosophers are examined. The seminal work of P. F. Colaizzi is deliberated and debated as a hybrid existential philosophy and phenomenological research method. The phenomenon under study is reviewed in a characteristic qualitative research framework that offers an overview of processes, protection, and rigor.

#### **Introduction to Qualitative Research**

Empiric research of dementia couplehood would demand controlled experimental conditions, identified hypotheses, application of many valid instruments and multivariate or dyadic statistical analyses to generate findings in the hopes of capturing a significant result in the life of a dementia spouse caregiver. Positivistic, objective and experimental research specifically looks at patterns and regularities. The methodology and resulting analysis seek explanation, causation, and prediction (Guba, 1990). However, quantitative approaches are found lacking in answers to inquiries in the physical, spiritual, psychological and experiential domains, suggesting a methodology then must be appropriately chosen to answer the question asked (Clark, 1998).

The word phenomenology literally means the study of what comes to light; or, the study of the phenomenon. A phenomenon is something that appears or manifests itself and as such the inquiring discipline of phenomenological psychology attempts to explore the phenomenon. Phenomenology is the descriptive (not explanatory) science (has an ambition to study

phenomenon rigorously) of consciousness (the major domain of the phenomenon); it emerges as a visceral awakening desire to understand all things not explained by positivistic empiric research (Martin, 2010). The central concept being that *consciousness* is *intentional* (von Eckartsberg, 1998).

Phenomenology has become a dominant philosophy and practice to guide knowledge generation and learning in nursing; but it also causes some confusion surrounding the nature of its philosophical origins, interpretation, the struggle between descriptive and interpretive models, and rigor of research study applications (Dowling, 2007; Norlyk & Harder, 2010). As phenomenologists critique ontology and epistemology of philosophers challenged with the pedagogy of phenomenological methodology (Colaizzi, 1978a, b; Giorgi, 1997), so too is there much conversation and debate over qualitative research, the narrow focus of qualitative health research, and even more narrowly, qualitative nursing research (Barkway, 2001; Crotty, 1998; Giorgi, 2000a, b). Authors (Crotty, 1998; Paley, 1998) suggested that naturally lived experiences selected for research by nurses are circumspectly identified, too subjectively described, and uncritical of the of the actual object and contextual essences. Their opinion was that nursing qualitative research fractures the interrelatedness of subject and object, mind and world, and Heidegger's *peculiar union* of the being of the world, with the being of Dasein, i.e.: the consciousness and understanding defined in being, being there, or authentic presence. The main message from their constructive criticism was for nurse researchers to focus on the concepts of bracketing, intentionality and discovering essences from the objective experience, not from the subjective narrative.

On examination, our simple and ordinary experiences of everyday life end up being very complicated and quite intricate. Even common events engage us at multiple levels expressed

counterintuitively as simply “being who we are” (Keen, 2003). Phenomenology is a way of seeing those experiences in a fresh way without prejudice, and descriptive of what appears to consciousness, and precisely how it appears. Its aim is to capture a richness in the experience as it unfolds to the subject who experiences it (McNamara, 2005; von Eckartsberg, 1998). By the nature of the phenomenon, this study mandated the use of the natural setting and free flowing dialog to allow discovery of perceptions and meanings of the dementia spouse caregivers’ relationship closeness phenomenon and resulting data. Denzin and Lincoln (2005) and Edward and Welch (2011) illustrated the captured phenomenological data as representations. Representations are conversations and interviews expressed in the everyday language of word and nonverbal expressions, and more. They include field notes, emails and memos as well as photographs, memos, and life manifestations of art, music, and poetry.

For example, as one looks at the ocean’s waves breaking on a beach, it can be measured in terms of degrees Fahrenheit, wave velocity, decibel level, climate conditions of barometric pressure and a certain color palate, but the empiric descriptive data fail to capture the feelings of reverberation in our chest, its invigorating nature and cleansing sensation, our feeling of diminution, the expansiveness of our world, and the belief in God or a greater spirit. Christine Bryden (2005), who was diagnosed with dementia in 1995, spoke about the value of human touch. Not as pressure per square inch, duration of contact or what location, but she described it as the sense of “touching our emotion and spirit” (p, 138) and an opportunity to enter reality- her reality as a person with dementia. Our sense of the value of, and for a thing, a person or an event is intentional. It is that act of consciousness that engenders the experience and thus purifies meaning to the individual. It was that meaning and subjectivity, the researcher endeavored to



discover with dementia spouses; and why a phenomenological study was an appropriate means to explore this life, and life-changing, experience.

In their analysis of what makes a phenomenological study phenomenological, authors Norlyk and Harder (2010) reported considerable variations of justification of the study, methodological approaches, terminology, and rigor. There were inconsistencies between studies and omissions, suggesting a critical need to articulate methodological keywords of the philosophical underpinnings, the phenomenological methodology according to the primary-referenced source, and the investigated phenomenon's elements. This study, as well as the manuscript, were guided by primary source philosophers and phenomenology academic experts.

Spiegelberg (1972), frankly and humorously recognized required limitations on the scope of philosophy in written discourse; as the distinguished author said, "One major threat for the present enterprise [his written history of phenomenology] is that it knows no natural boundaries." (cited in the Introduction, xxvii). At the same time, Churchill (2008) and Giorgi (2010) criticized recent doctoral dissertations for naming a multitude of philosophers believing that more is more relevant, and failed to remain true to a primary source's theory and methodology.

This study selected the descriptive phenomenology as practiced by the Duquesne School of Philosophy. Historical philosophers who were integral to the formation of that style inquiry are discussed. The study's keywords, philosophical jargon, and descriptive phenomenological terminology are defined in context and discussed throughout the method section. In the next section, Husserlian origins of philosophy are briefly reviewed, Duquesne's influence in the field and discipline of phenomenology is examined, and the author's interpretation of Colaizzi's phenomenology is presented.

## Husserlian Phenomenology

During the 17<sup>th</sup> and 18<sup>th</sup> centuries physicians, neurologists and neuroanatomists launched enlightened, popular and distinguished studies that were medicalized and sensation-bound using empiric methodology on the human body subject (Spiegelberg, 1972). Their contemporaneous philosophers were still grappling with ontology (the philosophical study of the nature of being), epistemology (the study of the nature of knowledge, justification, and the rationality of belief), logic and ethics. And, at the same time morality, religion, politics, and economics motivated free-thinkers and philosophers as an intellectual crusade to explore consciousness via existential thinking, i.e.: the examination of an individual thinking subject as well as the acting, feeling living human individual. In today's vernacular, they would be called social justice warriors when applying phenomenological thinking to cause equality. Freedom, free will or intentionality (mind-dependent) was the predominate value, but its primary virtue was authenticity. Existential thinking influenced both psychology and psychiatry (Churchill & Wertz, 2001).

Existential phenomenology grew out of a general attempt to study and know the concepts of consciousness and experience. Phenomenology was a German movement fathered by a mathematician, Edmund Husserl (1859-1938). Its motto was *to the things themselves*; it involved a distinct departure from traditional theoretical concepts as it concentrated on the "subjective" fullness of individuals. (Spiegelberg, 1972). Phenomenology is commonly understood at the most simplistic of levels, as the study of structures of experience, or consciousness. Literally defined it means the study of "phenomena" or the description of things as they appear, or as they appear in our experience, or the ways we experience things, and ultimately reduced to the meanings things have in our experience. It is the study of the *lifeworld* (Beyer, 2016). Husserl (1962) was seeking an indisputable origin, basis, and description of all human knowledge.

Colaizzi (1973) viewed phenomenological psychology as a descriptive discipline mediating between empirical psychology, an explanatory system, and Husserlian philosophy of existence.

Phenomenology studies the structure of different experiences through a person's perception, thought, memory, imagination, emotion, and desire; it also encompasses linguistics, social being, body awareness and deliberate actions. And as such, it is a philosophy, and a phenomenological theory of science (Keen, 2003). Husserl recognized his work was primarily philosophical, but that it had implications for the science of psychology, the study of behavior and mental processes. Psychology up until that point was a positivistic science fathered by William Wundt (1894), studying behaviors, memory, learning, perceptions, and senses in experimental labs full of tachistoscopes, chronoscopes, pendulums, electrical devices, timers, and sensory mapping equipment (Colaizzi, 1978a).

Husserl believed that in phenomenology, a process, “the phenomenological reduction” in which one would suspend all suppositions in an effort to describe the meaning of the individual's experience, would allow discovery of their very consciousness. He ascribed to the theory of knowledge known as epistemology and used the word *intentionality* (co-opted from Brentano) as the conduit of a person's perception, thought, memory, imagination, and emotion (Reiners, 2012; von Eckartsberg, 1998). Husserl used the conceptual term, *epoché*, to describe the critical need to refrain from judgment— bracketing (literally translated as parenthesizing), to allow one *to literally find astonishment in, and at, the phenomenon*. Bracketing demands the researcher set aside personal beliefs and knowledge to naively hear and observe the experience of the phenomenon, and allow things to speak for themselves. It is a voluntary, an active and a cognitive process that the researcher exercises. It suspends the world as we know it to be, and allows the researcher to interpret information with little interference from the researcher's world

or life experience, allowing the true meaning of the phenomenon under scrutiny to be revealed; thus, bracketing and *free imaginative variation* allow *phenomenological reduction*. Free imaginative variation was a process in which the object of the phenomenon would be varied in the imagination of the researcher, altering its constituents to test the limits (or constituents) to the point it retained its identity (von Eckartsberg, 1998).

Husserl discussed the phenomenological reduction, or the transcendental reduction, as not a function of facts or data, but the essence of the experience, much like the memory of a smell or, a feeling. (Husserl, 1962; van Manen, 2014). Singularly, descriptive in nature, and while preconceived opinions were set aside, or bracketed, conscious everyday *lifeworld* experiences could be described (Reiners, 2012). *Lifeworld* or lived experience is another phenomenological concept; per Husserl (1962), it is the foundations for understanding all human experiences. It applies meaning-making to a person's sum and total of experience and essentially defines their world. It is what individuals experience pre-reflectively, and without interpretation. In review, the epoché allows reduction which uncovers the phenomenon's *essence*, the innermost and fundamental aspect that makes a thing, something. Essence is not discovered with insight; it requires reflection, thought, and scrutiny. Essence is universal to phenomenon (Beyer, 2016).

Phenomenology's origin was related to the concept of *consciousness*, or how one views themselves, and an intersubjectivity of how one relates and sees another. It was a vehement response to the current behavioral psychology and empiric anatomists of the time. Humans are perceptive in nature, and a person interprets their experiences in real and imagined ways. With phenomenological inquiry, at the conclusion of epoché the researcher achieves the *transcendental ego*, or "the true self," thus allowing the open and naïve consciousness needed to

understand and find meaning for a particular phenomenon (Husserl, 1962; Beyer, 2016). Husserl engaged in pure descriptive phenomenology as a philosophy.

Martin Heidegger (1889-1976), a student of Husserl, is renowned for the seminal work, “Being and Time.” He is controversial because of his support for the Fascist Nazi regime; this remains a footnote in history, as his writings of phenomenology continue to be cited, discussed and taught worldwide. Heidegger rejected the phenomenology movement, and his mentor, with an alternate vision of Husserl and Descartes’ view of man as a subject confronted by objects with *Dasein* (Being There). He countered the epistemological theory with an ontological perspective and focused on hermeneutics, thereby developing interpretive phenomenology (Reiners, 2012; Wheeler, 2016). He believed Husserl’s phenomenology was limited to the appearance of objects, rather than what was unseen, or, which itself did not appear; he called this the *given-ness* of phenomena. He did not ascribe to the detached analysis of consciousness but instead focused on everyday experiences. His question was not about being, but it is the meaning of *Being* (Wheeler, 2016). It was a reversal of phenomenological method, shifting from what appears to *me*, towards a primordial– what is manifested from *other than me* (Janicaud, 2013). He united the philosophical styles of Dilthey (stress on the role of interpretation), Kierkegaard (human reality over abstract thinking and stressing the importance of choice) and Nietzsche (will to power and value systems) (Wheeler, 2016).

In his influential book (Stassen *Translation*, 2003, Heidegger examined at length the question of what is being, distinguishing it from being to *becoming*. He gave a concrete example of the failure to capture the essence of subject-object. He proposed when a carpenter is using a hammer and nails, the carpenter does not have to concentrate, and the object (nails) become essentially transparent, much like when we enter a room and turn a handle. Heidegger called it

ready-to-hand or Process Being. It is only when something goes wrong that the existence has any significance and enters our consciousness (subjective), i.e.: when the hammer is too heavy or the doorknob sticks. Then the context of carpentry, houses, rooms and purpose make sense. He called it present-at-hand or Pure Being in the world (Smith, 2016). Heidegger was a non-conformist. He is often considered a founder of existentialism because of his ontological roots and analysis of individual human being's mode of existence in the world. Heidegger engaged in pure interpretive phenomenology.

Existential phenomenology was also developing in France by Jean-Paul Sartre and Maurice Merleau-Ponty. They were influenced by Husserl and Heidegger. Sartre, originally a traditional philosophy student, was woke to the rebellion of the futile question of "I think I know something, but how can I *know* that I know what I know" (Bakewell, 2016). Similar to Heidegger's pure being and process being, Sartre engaged in the investigation of *in-itself* (en-soi) and the *for-itself* (pour-soi), which he proclaimed irreducible kinds of being, an ontology that is primarily descriptive and classificatory as opposed to explanatory. His descriptive method would move from the most abstract to the highly concrete. Somewhat related, and also of existential consciousness, Merleau-Ponty was absorbed by the structure of behavior, the experience of vision, or optics, and touch with its interminable reversibility of sensing as an impossible and incredible coincidence of *the touching* and *the touched* (Merleau-Ponty, 1962). Together they pushed their phenomenological arguments further than Husserl's original focus of intentionality towards a more deliberate, prereflective consciousness of intentionality and ontological freedom of choice within ourselves (Smith, 2016).

Philosophers of that time were 'thinkers' who invested time, were harbingers of work addiction, and often became emotional, argumentative and patronizing in all things philosophy.

Intellectual battles provoked growth of the human science. Martin Heidegger turned against Edmund Husserl, and later Heidegger's colleagues turned their back on his Nazi egalitarianism and anti-Semitic views; Merleau-Ponty fell out with Sartre, and even the French existentialist posse of Camus, Marcel, Sartre and Simone de Beauvoir differed in ideas during the extreme political ideology and suffering of World War II. Even when the giants of philosophy, Heidegger in Germany and Sartre in France met in 1953, it is recorded the meeting went badly and they spoke mockingly of each other (Bakewell, 2016). This reference is just to substantiate for the readers an appreciation that phenomenological philosophy is a work in progress that continues to today. It also suggests the influence of present media streams (books, movies, images and videos) that allows everyone the ability to comprehend philosophy. Rather than reading translated texts of ancient philosophers, the 21<sup>st</sup> century allows YouTube the capture of live dialog (Giorgi, 2013; van Manen, 2014).

Despite the philosophical disputes and controversies, the synergy of Husserl's descriptive phenomenology, or the study of knowledge and what "to know," Heidegger's interpretive phenomenology, an ontological view of "Being" and "Becoming," and the existential movement of free choice, together was extraordinary. Together they launched the discipline of qualitative studies in the human sciences and phenomenological psychology. Husserl and Heidegger's work formed the foundation for other 20<sup>th</sup> century European, British and American philosophers to pioneer phenomenological studies of existence, advancing its doctrine, and further apply it to human science (Churchill & Wertz, 2001; von Eckartsberg, 1998). It is often called the *new* phenomenology instead of *pure* phenomenology (Crotty, 1998; von Eckartsberg, 1998). It was renamed a movement, not a static philosophy (Spiegelberg, 1972). As phenomenological methodology grew, it accepted criticism and modification (Giorgi, 1970). Thus it branched out,

all with a desire to pedigree a procedure, as we see among others, in the Pittsburgh, PA, Duquesne School of Phenomenology.

### **Duquesne School of Phenomenology**

The 1960's United States boasted a fresh spirit of change and renewal. Multiple influences of the era of Humanistic Psychology dotted books and research with words like self-actualization, autonomy, creativity and self-transcendence. John F. Kennedy and Pope John XXIII proposed optimism and infinite possibilities (Smith, 2010). The Duquesne Group (specifically the 1947 faculty who created the original graduate program of a phenomenologically based Human Science Psychology), were at the precipice of new phenomenology.

Father Henry Koren, a member of the Holy Ghost religious order, taught Thomistic philosophy following Aquinas' principles and syntheses closely. He was keenly aware of the new visions of modern philosophers; and as department chair, he invited visiting professors, specialists in contemporary philosophy of science. In 1954, one distinguished guest professor was Herman van Bred, the director of the Husserl Archives at Louvain. It was then that Koren turned his attention to phenomenology and began translating phenomenology books and articles written by visiting professors. As faculty recruiter, Koren successfully brought another young Dutch Holy Ghost Father, Adrian van Kaam, to the department. In 1959, van Kaam announced his plan for a new psychology in a student newspaper article, *The Justice*, titled, "Freud and Anthropological Psychology" (Smith, 1983).

The newly emerging anthropological psychology intends to fulfill the need for synthesis, integration, and theoretical depth in the many vastly expanding fields of knowledge about man. The awareness of the necessity of this kind of function in



psychology has been increased considerably by the growth of existential-phenomenology. Existential-phenomenology's concentration on man's being and acting has made various psychologists aware of the need to understand in their deepest meaning the several findings, theories, and terminologies of the numerous schools of philosophy, psychology, and psychiatry in different cultures and to keep integrating them in an open, continuously growing and changing Gestalt. This task of anthropological psychology may be compared with the task of meta-biology in the biological disciplines and the rise of theoretical physics in the physical sciences, (Smith, 1983; as cited p. 260-261). The humanistic movement was launched in Pittsburgh, Pennsylvania.

Smith (2010) recorded the career of Amedeo P. Giorgi and the phenomenological movement at the Duquesne Center. Giorgi was educated at Fordham, taught briefly at Manhattan College, NYC, but worked as a research psychologist at Dunlap and Associates, Stamford, CT, focused on engineering projects. His brief teaching tenure was attributed to his overzealous critiques of his own subject matter, psychology. Giorgi met van Kaam through a mutual colleague and at their first meeting, van Kaam invited Giorgi to join the faculty. Giorgi hesitated. However, after this session, Giorgi read avidly phenomenological literature, and he took phenomenology courses at the New School for Research in NYC. Giorgi also visited the renowned center for phenomenology in Utrecht, Holland. There he discovered that none of the students or professors were actively engaged in doing phenomenological research; there was no existing methods. That discovery reaffirmed his decision to join Duquesne with the goal to establish an empirical phenomenological research methodology.

Paul Francis Colaizzi was born in in 1948 and passed away on Nov. 25, 2010. He was a proud Marine and received his bachelor's and master's degrees in mathematics, teaching and

psychology. He taught at Virginia Commonwealth University in Richmond, VA. His doctorate was in existential-phenomenological psychology at Duquesne. He was a student (Colaizzi, 1969) and colleague of Giorgi (Giorgi & Colaizzi, 1966) and joined the Duquesne faculty in 1970. Colaizzi married his academic background in sciences and psychology, with the philosophy of phenomenology, but did so in his own hybrid manner. He was influenced by philosophers Husserl, van Kaam, and, Amedeo Giorgi, as well as Heidegger, Merleau-Ponty, Sartre, and Thomas Kuhn's notion of paradigms. He offered respect to Spiegelberg (1904-1990), the phenomenological movement historian, had connections as co-student with Rolf von Eckartsberg (1932-1993) and was a professor to Scott Churchill, who currently writes voluminously about the nature and methodology of phenomenology.

**Dr. Paul Francis Colaizzi.** Phenomenology begins with a naive experience and improves upon it by, not eliminating the subject from the knowledge, but explores and clarifies the connection; there are many philosophies and many methodologies (Keen, 2003). This study employed the method and art of phenomenology ascribed to by Colaizzi. His comments in his dissertation (Colaizzi, 1967) about phenomenology are succinct, slightly irreverent, and most of all, easily understood. He was, to begin with, an empiric scientist. He gave full shrift and dedication to Husserl, "father of phenomenology" but thought it presumptuous to attempt an explanation of underpinnings. It was the 1960's, and as he states,

...phenomenological psychology must be considered a recent movement in comparison with other established schools of psychology. But despite the 'recency' of its development, it is characterized by a vitality that has resulted in an impressive amount of literature in the United States and Europe. Due to the sheer bulk of this literature and the variegated issues contained therein and

certainly also due to the fact that it has not yet attained any real unity or consolidation, it is impossible at the present to succinctly express its meaning and nature (as cited in Colaizzi, 1967, p. 1).

However, Giorgi (1970, 2010), Colaizzi's colleague (Giorgi & Colaizzi, 1966), professor and dissertation committee member (Colaizzi, 1969), ably defined the phenomenological method in Duquesne psychology, much like Van Kaam, as using a systematic and explicit attempt to observe and describe all essential characteristics from the world of the phenomena as it is presented to us. He stated phenomenology is not inductive, deductive or abductive. It is descriptive and intuitive yet with a goal to achieve parity with an empirical scientific scholarship. Giorgi disagreed vehemently with the validation step within Colaizzi's methodology. Colaizzi (2004) disagreed passionately with the term intuition, that as translated from Kant's German it meant purely to look at in a way to problem solve, not like the Latin translation to use hunches or understand without proof, evidence or conscious reasoning. Still, almost fifty years after Colaizzi's dissertation, Colaizzi and Giorgi agreed that methodology is still a work in progress (Colaizzi, 2004; Giorgi, 2011).

Colaizzi found his personal approach to phenomenology; and with a Husserlian influence, believed that phenomenology should focus on descriptive essences. Like Heidegger, he viewed the individual as being *already* in the world, versus that what is coming from "what is within"—an internal perspective. Colaizzi's method for doing research was adapted from his dissertation in which he compared phenomenological methods. Colaizzi wanted to relate Adrian van Kaam's multi-sample phenomenal study (ps) to the method of how a pure phenomenological philosopher (Husserl) might reflect on the meaning of a phenomenon, he identified as one-sided, which he called the Individual Phenomenological Reflection (IPR). He then added the process he

called the Empiric Phenomenological Reflection (EPR) method, *his* method for discovering the fundamental structure of the phenomenon (the relative essential elements that together provides a full description of that phenomenon). What he wanted his dissertation to show was that all the data collecting in the world would not be good unless one had first engaged in a genuine phenomenological reflection oneself, an IPR, to guide any subsequent collection of data and its analysis; and that any study analysis must be done with extreme attention to the active process of reflection. This suggests taking the epoché to a higher level and employing Merleau-Ponty's notion of thinking-reflecting-reviewing as a colossal activity. Neuroscientists discuss this capability as the most complex function of the body (Ted, 2014)

Colaizzi's philosopher influences are noted in that previously described reflective activity; likewise, it was expressed by Merleau-Ponty as a strange power that possessed one of being ahead of itself, suggesting racing thoughts, connections, reconsideration, grasping for understanding and meaning making. It is a more intense degree than organizing data, seeing commonalities and face-value judgment. It requires dwelling on the elements and description of the phenomenon and methodically examining processes of what might be, what could be, and what is implicitly revealed, and what is the intentionality (Rao & Churchill, 2004). Imagination on the part of the researcher seems counterintuitive when bracketing, but suggests a keen free variation of thought without judging. In all, Colaizzi was pragmatic like Merleau-Ponty in that situational phenomenon is contextual, that the essences (experiences) of phenomenological psychology become "factual-essences," and they expanded to embrace the absolute richness of concrete human existence (1973). However, also, like Husserl, Colaizzi recognized that personal predispositions and biases must be recognized, bracketed, but can never be completely eliminated. To make phenomenology, even more, a non-conventional and perplexing approach,

Merleau-Ponty (1962) advised an important lesson, which phenomenological reduction teaches us that it is impossible to completely reduce a phenomenon.

Colaizzi like so many other methodologists influenced by Heidegger and Van Manen did not like the idea of codifying steps for everyone to follow. For Colaizzi, they had only pedagogical value. The Empirical Phenomenological Reflection was his empirical process, that yet remains abstract to some; a method, however, that Giorgi got excited about and wanted to systematize to provide the gravitas for phenomenological research. Scott Churchill, a student of Colaizzi, described the earnest drive at Duquesne in the 1970's to design a phenomenological methodology; it was van Kaam's goal for the department! *"Giorgi wanted the method to appear scientific and pass the litmus test, so to speak of science - replicability, operationally defined steps, rigorous reflection, systematically applied to every piece of raw data. So, the version that Giorgi produced, though grounded in this early work of Colaizzi under Giorgi's supervision, focused more and more on the steps of the procedure for data handling. Giorgi always said that the hardest part of the method to describe was the reflective step transforming the data into the 'structural description'"* (Churchill, personal communication)

### **Colaizzi's Phenomenological Method**

In Colaizzi's dissertation and subsequent publications (1967, 1969, 1971, 1973, 1978a, b, 2001), he set an exemplar of scholarly work in which he distinguished the differences between Husserlian philosophy, and van Kaam and Giorgi's descriptive phenomenology. Even according to his own words (2001), Colaizzi's seven-step method for a phenomenal study is what was embraced in the maelstrom of new phenomenological research; but it was not quite his whole archetype of research. Colaizzi applied a hybrid methodology in which primary sources, philosophers Husserl, Heidegger, Sartre, Merleau-Ponty and Kuhn, merged with an

entrepreneurial blending of a self-described phenomenology that seemed to intermingle descriptive and interpretive concepts. He admitted there was ambiguity of the phenomenological movement in America, but reaffirmed the current phenomenological psychology was employed to be descriptive and experiential as opposed to natural science's explanatory methods. Colaizzi questioned, though, the adequacy of the descriptive method, as it left unanswered crucial question concerning what was to be described (the phenomenon itself) and how the descriptive tactics would be executed to obtain the descriptions. Colaizzi knew, in order to qualify as a strictly scientific method, phenomenological psychology knowledge must be verified by experimentation (Colaizzi, 1973).

As previously noted, Colaizzi's methodology sought to surpass two specific phenomenological methods (Husserl's IPR and van Kaam's ps) using his own design of an Empirical Phenomenological Reflection. Colaizzi described the data capture in two very different ways. The Individual Phenomenological Reflection IPR is like an upside-down funnel in which the stream of consciousness quickly becomes wide-ranging and far-reaching with all of the life world possibilities. The operations employed are reflection and imaginative presence. The "individual" in IPR is not a single subject or case study; it designates a reflective activity as that of the individual phenomenological researcher (Colaizzi, 2001). This is called Operation One.

Operation One derives a researcher's data from his or her personal experiences amplified through free imaginative variations. Colaizzi reintroduced personal introspection into his empirical methodology and considered it a necessary first step as it would reveal the researcher's precomprehension of the experience to be studied. The benefits would be to help other researchers who might want to continue examining the phenomenon, and it is a foundation for

the researcher for the reflections on the sample participant's protocols (von Eckartsberg, 1998). Polkinghorne (1989) describes IPR in context with the active self-evaluation, bracketing process, and as a preparatory step to gather data from research subjects. However, most researchers just jot down those reflections, perform sensitizing exercises, and identify anticipations that would alert interviewers to possible themes by subjects and also are used for reference during *ps* analysis. He remarks that Colaizzi labeled the process IPR with a fuller more reflective technique (Polkinghorne, 1989).

Operation Two is the phenomenal study itself. In the second execution of a phenomenological method, Colaizzi followed van Kaam's technique for a phenomenal study, staying at the lowest data analysis level for discovered descriptions; he did not go to the *eidetic* level (mental images having unusual vividness and detail, as if actually visible) by means of free variation in the imagination. Thus, the *ps* or, Operation Two, could be described as an empiric logical deduction. The processes resulted from the transcripts of interviews which were called protocols, imaginative (bracketed) listening, and protocol analysis itself. The data was derived empirically and from a plurality of subjects. The process allows that repetition of common findings and organization of that data allowing the researcher to derive a shared fundamental Description, referring to the description of the phenomenon as it is experience is recounted. The data derived reached a point in which repetitions in an experience belonged (Colaizzi, 1973). Giorgi (2010) offers this pearl of wisdom; the researcher must be faithful to the experienced phenomenon: if there are repetitions in an experience, then they belong there and have a disciplinary meaning. Figure 10. Identifies Colaizzi's Operation Two procedural steps for analyzing written protocols. Conventional Colaizzi studies identify the seven (or eight) steps as the methodology. The author suggests the blue printed areas in steps 6 and 7, are actual

components of Operation Three, the Empirical Phenomenological Reflection. And so, in keeping with an original intent to replicate Colaizzi's phenomenological learning study, the author describes steps 3 and 4 fully.

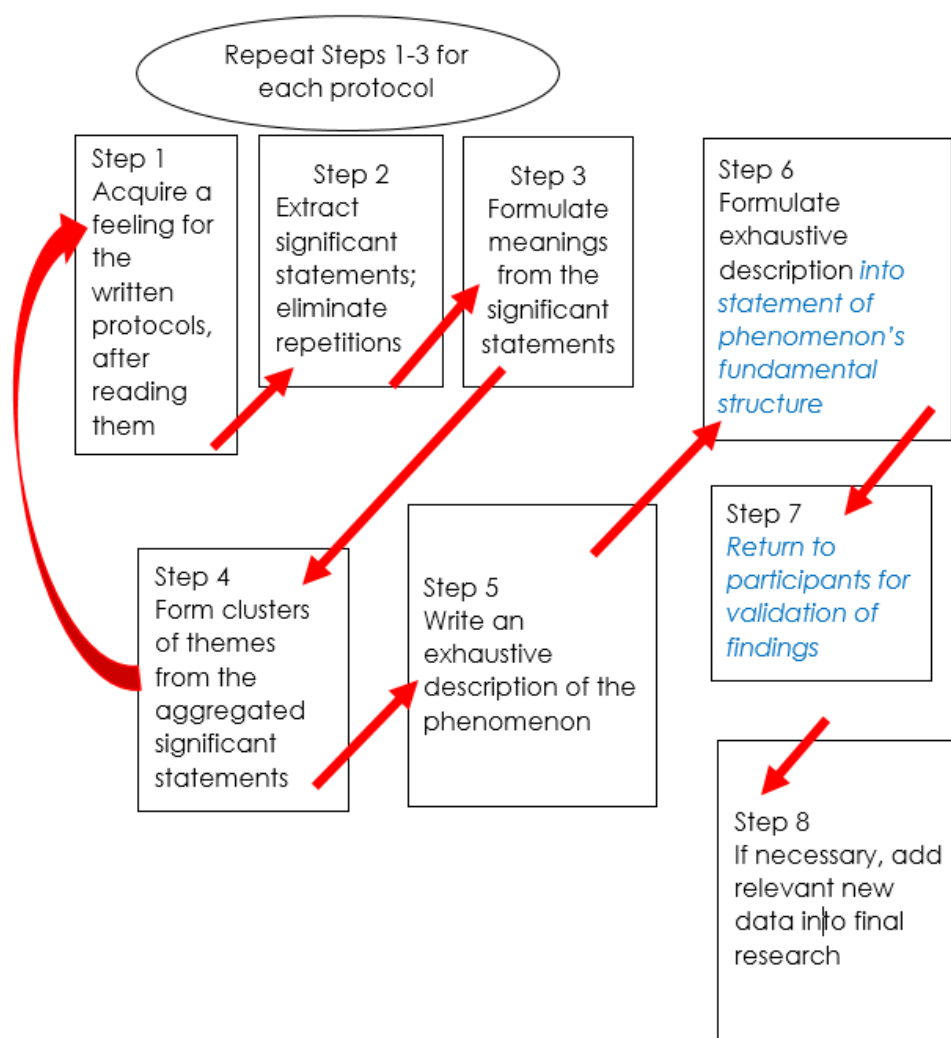


Figure 10. Colaizzi's Phenomenological Method Procedural Steps for Analyzing Protocols

It is in Operation Three that the fundamental description (the essence of the phenomenon as it is experienced) becomes richer, by the method of EPR. Empirical Phenomenological Reflection did not refer to just objective data from the dialogal interviews, but it also refers to *possibly* objective data from any sources, except the investigator. It can also be viewed as a narrowing spiral, as information and reflection synthesize into the fundamental structure



(Colaizzi, 2001). Colaizzi remarked that simple essential themes could be identified. Colaizzi is also clear about the nature of reflection; it is abstract, does not always follow the indicated order, and the steps tend to overlap (Colaizzi, 1973, 1978a, b).

Then in Operations Four Colaizzi employed EPR to reveal what his method could yield, or potentially yield (S. Churchill, personal communication). Step Four repeats discovery. Each of the significant themes is interrogated. The comparison of IPR and EPR procedure is an individual reflection, without empirical data, and with reflection on the implicit dimensions of the fundamental structure (the essence of the experiential phenomenon as it is revealed by explication; the process in which the constituent elements of a thing are revealed without the addition of new elements) (as cited in Colaizzi, 1973, p. 33). This is co-constituted because the researcher and the co-researcher participants derived the final fundamental structure; the essential constituents that are elemental to the phenomenon are revealed. See Figure 11., for the author's interpretation of the duality of studies (IPR and ps) and the combined yield. This can be called a constructionist approach.

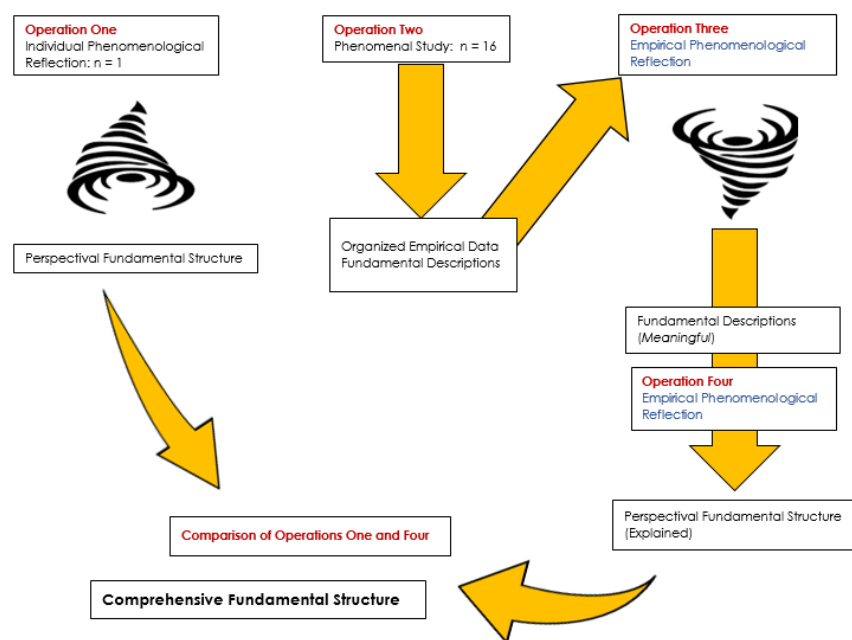


Figure 11. Colaizzi's phenomenological psychology method of research.

**The Author's Individual Phenomenological Reflection.** Munhall extolls the exemplar, “becoming phenomenologic” toward the world and encourages one to think phenomenologically (2010). The benefit she describes is the ability to parse perspective and approach, in that as a phenomenological researcher: the perspective guides the research study and ways of seeing and understanding the phenomenon; the approach comes later in executing the study as a methodology. In summary, it is important to immerse oneself in the underpinnings of the philosophers’ perspective and, in Churchill’s (2008) editorial, “Be true to your school,” be faithful to the phenomenologist’s methodology.

As a first step to execute a primary reflection on the phenomenon under study, to academically perform the praxis of Individual Phenomenological Reflection and finally to understand the nature of IPR, the author identified various dissertations and how the authors depicted their personal IPR (See table 3).

Table 3.

***Examples of individual phenomenological reflection used in doctoral dissertations and Colaizzi phenomenological method.***

| Dissertation Title  | Individual Reflection Method   | Author                   |
|---|--|--------------------------|
| Interpersonal Evaluation in Everyday Encounter  | Author’s recollection of two specific experiences of an ‘encounter.’ | Barnes, R. M. (1969)     |
| The Descriptive Methods and the Types of Subject-Matter of a Phenomenologically Based Psychology: Exemplified by the Phenomenon of Learning                                   | Author’s self-administration of ‘learning test.’                     | Colaizzi, P. F. (1969)   |
| The Phenomenology of the Natural Athlete  | Author’s biography of being a child sports enthusiast.               | Alapack, R. J. (1972)    |
| The Lived Structures of Being-Embarrassed and Being-Ashamed of-Oneself: An Empirical Phenomenological Study   | Author’s personal experience of the phenomenon.                      | Vallelonga, D. S. (1986) |
| Dying: An existential-phenomenological investigation of the experience of being with a dying person, who was aware of being in the dying process, and who had asked you to be | List of author’s personal preconceived notions.                      | West, T. B. (1994)       |

with him or her, as he or she went through this process

An Existential-Phenomenological Investigation of the Experience of Old Age in White, Upper-Middle Class Elderly Women

List of author's personal biases. Infante, N. (2001)

Surrounding Death: A Phenomenology of the Withdrawal of Life-Sustaining Treatment

Author's recollection of pediatric trauma patient.

Jacobs, B. R. (2002)

The author's personal IPR began with an understanding of phenomenology, by attempting to frame the phenomenon with empathy, compassion, and mindfulness, as those are the values the author pledges in her medical practice. Being a pragmatic person, the author initially listed the medically oriented elements essential to the phenomenon (see Table 4).

Table 4.

***Individual Phenomenological Reflection: Dementia symptom interference with elements of relationship closeness.***

| Marital Element of Relationship Closeness   | Cognitive Impairment (CI)<br>Neuropsychiatric Symptom (NPS)<br>Functional Loss (FL)  |
|---|--|
| Meta-communication <ul style="list-style-type: none"> <li>• <i>Meaningful discussions</i></li> <li>• <i>Problem solving</i></li> <li>• <i>Planning</i></li> <li>• <i>Couplehood – “We-ness”</i></li> <li>• <i>Conflict resolution</i></li> </ul>        | CI: inattention, memory loss, executive disorder, agnosia/anosognosia, aphasia, visual-spatial impairment<br>NPS: aberrant vocalizations, aggression, agitation, anxiety, apathy/indifference, delusions, disinhibition, dysphoria, elation/euphoria, hallucinations, irritability/lability<br>FL: fatigue                                     |
| Speech & Language <ul style="list-style-type: none"> <li>• <i>Articulation of sentences</i></li> <li>• <i>Contextual dialog</i></li> <li>• <i>Non-verbal communication</i></li> </ul>   | CI: inattention, memory loss, executive disorder, agnosia/anosognosia, aphasia, visual-spatial impairment<br>NPS: aberrant vocalizations, aggression, agitation, anxiety, apathy/indifference, delusions, disinhibition, dysphoria, elation/euphoria, hallucinations, irritability/lability<br>FL: generalized muscle weakness, poor phonation |
| Intimacy <ul style="list-style-type: none"> <li>• <i>Proximity</i></li> <li>• <i>Affection</i></li> <li>• <i>Emotionality</i></li> <li>• <i>Couple Connectedness &amp; ability to reminiscence</i></li> <li>• <i>Satisfaction in partner</i></li> </ul> | CI: inattention, memory loss, executive disorder, agnosia/anosognosia, visual-spatial impairment<br>NPS: aggression, agitation, anxiety, apathy/indifference, delusions, disinhibition, dysphoria, elation/euphoria, hallucinations, irritability/lability<br>FL: frailty, fatigue   |

|                   |   |
|-------------------|---|
| Sensorium         | CI: inattention, memory loss, executive disorder,<br>Anosognosia, apraxia, visual-spatial impairment<br>NPS: aggression, agitation, anxiety, apathy/indifference,<br>delusions, disinhibition, dysphoria, elation/euphoria,<br>hallucinations, irritability/lability<br>FL: frailty, fatigue, impaired olfactory nerve, tremors   |
| Shared Activities | CI: inattention, memory loss, executive disorder,<br>agnosia/anosognosia, apraxia, aphasia, visual-spatial impairment<br>NPS: aberrant motor disturbance, aberrant vocalizations,<br>aggression, agitation, anxiety, apathy/indifference, appetite and<br>eating disorder, delusions, disinhibition, dysphoria,<br>elation/euphoria, hallucinations, irritability/lability, sleep<br>disorders<br>FL: frailty, fatigue, gait problems & falls, incontinence, tremors,<br>ataxia |

The second part of the author's Individual Phenomenological Reflection was taken from her personal and poetic journal. It is her life's "field journal." It was a diary of thoughts, words and general commentary on her life, her interactions with people, her current interests, and the world in general. Since early 2016, the author had been preparing this research study and so wrote margin notes about her thoughts of those couples she would interview and some of the couples within her medical practice. These are some of the entries (Table 5).

Table 5.

***Individual Phenomenological Reflection: Individual Biases and Preconceptions  
A Perspectival View of Dementia Spouses***

Friday, May 20, 2016

The spousal experience of closeness is so intimate and mysterious. But what happens when dementia symptoms intrude on the relationship; a husband, or wife, and now has a partner living with them, who no longer sees them as

*who they are,*

*or, who they were,*

*or, who they were together,*

yet they are still in a wedded bond with vows and testament.

Sunday, May 29, 2016

They live within walls, with silence and noise,  
with memories forgotten, and abilities no longer ready and able,  
with home and business and artful skills lost, and energy all but gone...

Then suddenly, there are fleeting moments of clarity and insight— a spot on remark, here and there, and unpredictable, unexpectedly, things are as they used to be:

a touch,

a gaze,

a thought or

a laugh, remarkably like a lightning bolt.

In a heartbeat, it brings back the connection and a subconscious meaning. But then **it** is gone.

Wednesday, June 8, 2016

What happens when your loved one with dementia calls you his mother, her brother, or the dreaded, “I don’t know you.” Are you no longer a wife or a husband? Likely not, but there is a mighty sorrow, and anger, impatience, frustration, fear, and hurt. It upsets the pendulum of life.

When that spouse with dementia, who once had character, decorum, independence, intentionality and reason, now, his or her behavior and character are at odds with the personality well known (perhaps for 60 years). I know and see, even with dementia, personality endures with grand illustrative and primordial streaks of humor, or art, or precision, or values despite this disease. The spouse says they are fading, vanishing, and disappearing. I try to help, I say, “Don’t take it personally; it’s the disease.” Do I balance empathy with reality? *I need to stop saying that.*

Monday, June 13, 2016

It is the loss:

for husband, for wife, and for couple,

who together, can’t, or don’t, or won’t, or no longer speak the thoughts, the questions and answers, the dreams and decisions, or are even capable to jointly choose a future together as a couple. Will they live together from now on, or not? Is it too hurtful so as to cause separate homes; or will they continue on at present, in ambiguity— living together separately.

Wednesday June 22, 2016

Who is this person with whom they pledged a life together?

It was with love or promise, with potential or capacity, with positivity or complacency, and a million different reasons they joined in couplehood.

Now facing dementia, a couple, none the less, with a twofold identity as one, with a sum greater than its parts, at one time had a mutual design for completing life together to the end.

Thursday, June 30, 2016

And now there is transformational change. Do husbands and wives think or say, *they* aren’t my spouse anymore? But yet, I see there is still some connection between the two.

Is there a choice for action, or not? And is this pragmatism, compassion, or agape?

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The Individual Phenomenological Reflection was an imperative for Colaizzi (1973, 1978a); he recommended that the researcher must identify their conceptions and knowledge, as well as identify with the phenomenon. However, it is not a lived experience for the researcher as it is in the phenomenal study participants; it is through imaginative variation and/or memory that the researcher appreciated and understood the object of the phenomenon. In executing an IPR, the author used her empiric life knowledge and experience, much in the Carper's (1978) 'fundamental ways of knowing' in nursing. Polkinghorne (1989) reported data from self-reflection to be beneficial in locating the presuppositions and biases the researcher holds. It also illuminated the boundaries and dimensions of the phenomenon before actually executing the study and starting interviews. Spiegelberg (1980) stated that vicarious experience with a phenomenon can be accomplished with imaginative self-transposal or a cooperative encounter. The IPR grounded this study; it identified themes of temporality, loss, love, and hate, limited choices and endurance, sometimes with humor sometimes with pain. A fuller explanation of IPR meaning is discussed in Chapter Five Findings.

### **Research Procedure**

The purpose of this phenomenological study was to describe the experience of spouse caregivers' relationship closeness to a husband or wife with dementia with all their cognitive and neuropsychiatric symptoms, essentially living a dementia experience day to day. The underlying assumptions of this research was that spouse caregivers' relationship closeness in the presence of dementia, transcends a traditionally defined subject (spouse) – object (RC) distinction. The goal then was to understand relationship closeness with the impact of dementia on the caregiver's emerging sense of themselves— an awakening of subjectivity in the world, albeit a dementia

world. The author focused on the lived experience of marital relationship closeness with an emphasis on awareness of dementia in the caregiver's life.

Caregivers described relationship closeness from their own viewpoint, not an a priori definition taken from instruments or prompts with words of bond and affection, and without direction to attach dementia symptoms to RC or life experience. By choosing spouse participants who have an established connection with the care-recipient, and report more time and hours conveying elements of care, the author gained insight into the ways they perceived RC, described CI-NPS and made meaning of their relationship closeness in a dyadic life with dementia. See Appendix E. for Approval to conduct this study received from the University of Connecticut Institutional Review Board and CITI certificate for Treatment of Human Subjects.

**Target Population.** Data collection from human subjects for this research was collected from August 2016 to November 2016. The research site was Southeast Connecticut (SECT). The desired participant population was limited by five inclusion criteria: 1) English speaking, 2) community-dwelling, 3) male and female dementia spouse caregivers 4) who co-resided with their spouse 5) who had dementia. The diagnosis of dementia was articulated by the spouse's self-report and that the disease was diagnosed by a Primary Care Provider, Neurologist, or another provider or clinic.

The physical health risk was minimal, but most participants in phenomenological studies are subject to anxiety and stress during the interview. When discussing an inherently sorrowful topic such as dementia of a loved one, it was expected that participants might display emotions reflecting grief, anger, despair and angst (Marwit & Meuser, 2002). Mayer (2001) researched chronic sorrow of dementia caregiving spouses and also captured emotions of guilt, remorse, and melancholy voiced by long-term caregivers. Although categorized as negative feelings,

articulating these authentic emotions could be therapeutic. William Shakespeare in *Macbeth* (Act IV, Scene III) states, “Give sorrow words; the grief that does not speak knits up the ‘o-er’ wrought heart and bids it break.” With the increased potential for depression and desire for psycho-social and emotional distress, all caregivers were given a handout that supplied bereavement support services in Southeast Connecticut, signs of depression, and strategies to find treatment for emotional health (see Appendix F).

The intent of the qualitative research was to use purposive sampling; the sample was biased to fulfill the need for the study and research questions (Beck, 2016). The participants were called co-researchers, as they were knowledgeable about the phenomenon being studied (Colaizzi, 1978a). Giorgi (1997) recommended a minimum of three participants; Colaizzi (1973) enrolled a sample of twenty-two students. There are no rigid guidelines. The participant sample was concluded with saturation (Munhall, 2007); the sixteen-participant sample resulted in accomplishing the aim to understand the phenomenon through adequate exposure to the qualities of the experience (Colaizzi, 1978a). Snowball sampling did occur. The in-person interview took approximately 60-90 minutes. To accomplish participant validation, follow-up interactions, via phone, email or in-person, took an average of 10 minutes.

**Recruitment.** An announcement to recruit participants was made via four private Dementia Caregiver Support Groups in SECT, the four Connecticut M-Teams, and through brochures placed in possible areas of senior participation. Connecticut’s Senior Resources, the Eastern Connecticut regional catchment area Agency on Aging, provides four geographically different multidisciplinary professional peer networks (called “M-Teams”). M-Teams focuses on elder issues, shares resources and programs, and offers a monthly platform for confidential case



discussions. Facilitators of both support groups and M-Team freely allowed marketing material to be overtly displayed and disseminated during meetings without pre-approval.

Recruitment postcards with perforated tear-off mailers, descriptive brochures, and recruiting flyers with rip off contact slips (per UConn template; see Appendix G) promoted the call for volunteers. Postcards, brochures, and flyers were available at the Caregiver Support Group meetings; M-Team meetings; the Groton, Stonington, Waterford and Ledyard Senior Centers' community informational display; and the Groton, Mystic, Stonington, Gales Ferry and Waterford Libraries' community events bulletin boards. Potential participants were screened by telephone and if eligible according to inclusion criteria were invited to participate in this study. Spouses interested in participating called the author's study cellphone number or emailed the student researcher. Dementia spouse caregivers were able to discuss screening for eligibility, instructed in participation steps if desiring to enroll, and set preferences for meeting with the student researcher. Participants met in a place comfortable and net neutral: their home, a library, senior center or cafe.

**Procedure.** The scheduled visit included an introduction, validating competency to consent, obtaining a signature for consent (see Appendix H), and digital-recording of the research study question and dialog. The specific open-ended question for participants was, "Please describe your relationship closeness with your *husband/wife* as you feel it... with all of *his/her* dementia symptoms and behaviors. Please share all of your thoughts, emotions, opinions, in as much detail as you can, until you have nothing more to add." The question was printed in large font, on a card in front of the participant, to which they could continually refer during the interview. Clarification questions were used during the interview.

Colaizzi's hybrid methodology employed intuitive and interpretive processes, and the participant caregiver was referred to as the co-researcher. This diverges from typical descriptive phenomenology of Giorgi and van Kaam. Colaizzi merged IPR, the *ps* and cooperative work with the participants to yield comprehensive results. The interviews, called protocols, were informal and were carried out in a conversational style. When the caregiver had no more to say in response to the topic, the digital-recorded session ended. The researcher collected field notes, observations and telephone records as needed. Notations were made later while listening to taped interviews, transcribing the conversations, reviewing the protocols, reflecting upon individual interviews, and via an ongoing continuous literature review.

This study's general opening question was asked of participants, honing-in on descriptions of deep, meaningful thoughts and memories. The second part of the caregiver interview was the completion of demographic questions (see Appendix H). A National Institute on Aging (2016) book, "Caring for a Person with Alzheimer's Disease" and a fifteen-dollar gift card were given to the participant.

**Analyses.** The analytic phase was performed as per Colaizzi's exemplar (1969, 1973, 1978a). The Individual Phenomenological Reflection, the phenomenal study, and the Empirical Phenomenological Reflection were employed (Figures 7 and 8). Colaizzi's step-wise phenomenological method guided the phenomenal study of sixteen participants. The steps are:

1. Read all of the subjects' descriptions in order to acquire a feeling for them.
2. Return to each protocol and extract significant statements.
3. Spell out the meaning of each significant statement, known as formulating meanings.
4. Organize the formulated meanings into cluster of themes.
5. Refer these clusters of themes back to the original protocols in order to validate them

6. At this point, discrepancies may be noted among and/or between the various cluster.

Researchers must refuse temptation of ignoring data or themes which do not fit.

7. Results so far integrated into an exhaustive description of the phenomenon under study
8. Formulate the exhaustive description of investigated phenomenon in as unequivocal a statement of identification as possible.
9. A final validating step can be achieved by returning to each subject asking about the findings so far (as cited in Beck, 2016, pp. 136-7)

Data control for significant statements, formulated meanings and themes used Pro NVivo 11 Software (QSR International). To understand the data organization, reflection process and theme assignment, the following example is provided to clarify the trail from formulated meanings to clusters of themes.

One spouse shared the following significant statement, *“how would I describe this, we are almost going on habit of how we always are with each other, well I just call it home life, I call it home life. ...because we have both been retired and home together, there is a kind of routine to your days and so it’s kind of habitual.”* The formulated meaning was reported as “Habits are important and maintain the couple’s relationship status quo; it offered comfort and was predictable.” The meaning was initially coded in three draft descriptive subjects as “rituals,” “comforting behaviors,” and “predictable vs. unpredictable.” The reflective process was driven via technology software that allowed easy click and drag reformatting of themes and repositioning of statements and meanings. However, this study’s process also included printing out NVivo summary reports, reassigning theme titles and incorporating other participant protocols. The investigator used multi-color ink, notations, highlighters, Post-it® notes, and a white board to further afford a personalized phenomenologist’s psychomotor activity as a pivotal

analysis procedure step. The praxis allowed the researcher time to dwell with the data, know the experience and facilitate the emergence of parsimonious themes.

The “ritual” theme was then upcoded to “coping,” and finally after EPR and intersubjective comparisons and illustrations, the meaning was categorized as an essential element to a primary theme called “I Respond to the Dementia: Balancing the Scales.” This is an oversimplified description of the process in which a researcher contemplates the given facts of a protocol to the implicit and intended *meaning* of the participant’s experience. Churchill and Wertz (2001) described this dialectical ballet as a movement from part to the whole, and then back to individual parts from the sense of the whole. Each protocol is analyzed within its own right and yields individual phenomenological structures. The researcher sees convergent and divergent connections among the various protocols to constitute the essential or invariant meaning and structure of the experience.

**Rigor.** Psychometric reliability in studies are measured, the error is proposed, and theories of sampling are determined, which gives suggests relative meaning. These are concepts at odds with human subjectivity. Therefore the criteria to establish reliability in human research is grounded by intersubjectivity, speech, and memory. This amounts to a perspective, also called the participants’ perception, which by what they say, truth is found— albeit their truth. Because their perception, language and memory cannot be nullified, it is something like ‘a good error’ (Wertz, 1986). Beginning with credibility as a representation of truth, Guba (1990) demands the findings be faithful and accurate to the phenomenon under study. This would suggest comprehensive transcriptions, field notes and keen observation and hearing are prominent skills required for the phenomenological researcher.

Qualitative research can stand alone as a rigorous method of research. It has been found credible with external validity and reliability (Beck, 1993). A number of methods were used to assure rigor of the study. They included: Institutional Review Board Approval from the University of Connecticut (UCONN), maintenance of an audit trail, informed consent of participants, and intermittent consultation with the researcher's University of Connecticut Doctoral Committee. Records were checked for required documents, signatures, contact information and consistency with research proposal guidelines. Each time the investigator completed work on the project, files and hard drive storage were placed in a locked cabinet. Surnames and proper names were altered on the written transcriptions.

Transcription of digital recordings allowed the researcher to dwell with data, capture audible non-verbal expressions and attain a good command of the protocols' contents. The investigator enhanced the rigor of data and interpretation using reflective journaling, multiple keyword searches on protocols, and the review of NVivo summary reports, especially during the analysis phase. Following methodical steps, remaining true to Colaizzi's exemplar and member checking with participants provided congruence. Creating an audit trail is essential in research to establish rigor, authenticity, and trustworthiness commensurate with qualitative research data collection, interpretation, and findings. Periodic searches and scoping was performed on original protocols and NVivo data, thus establishing data and interactions were credible, accurate, dependable, transferable and confirmable. Owing to the sole researcher nature of dissertation research, no other investigators provided reliability or fidelity checks.

Of important note, it was incumbent upon the author to reserve presuppositions, IPR and medical and technical knowledge during the interview process. The interview then enabled the participants' free flow of memories, feeling and descriptions, thus implementing a type of

bracketing from the investigator's view. This one-way sharing of the experience fulfilled fidelity to van Kaam's phenomenological approach. Strict adherence to Colaizzi's steps and use of direct quotations from participants supported credibility.

Meaning and interpretive phenomenology and their crossover with Colaizzi's method are clarified in Chapter Five. The narrowness of the purposive sampling and demographic data will be discussed in the findings section and again with transferability in the limitations of the study in Chapter Five.

**Protection.** This research study is underpinned with the comprehensive steps of human subject protection as noted in IRB application (see Appendix E). Confidentiality of the participant in this research study was paramount to maintain. Recording of names, addresses, and other contact information was kept in a secured locked filing system. This included the original contact information as noted in Appendix H. Data entered on the computer did not include names. Electronic files included spreadsheets for demographics, audio files and documents for dissertation manuscript; they were kept on a remote hard drive and locked in a cabinet. The key was kept in a separate location, known only to the researcher.

Ongoing data collection and analysis took place throughout the study via an mp player and audio file software, verbatim transcribed interviews by the author, handwritten field notes, a personal reflective diary, electronic files for data collection storage, and Excel computer software, allowing matrix method of data management and analysis. This allowed a transparent, auditable framework to follow progress, analyze and critique the research process and methodology of the study. Credibility and confirmability of findings were enhanced by keeping these careful records. Edward and Welch (2011) reported an extension to Colaizzi's analysis to include expressions of life metaphors including – art, music, poetry, pictures, etc.; the author was

sensitive to those symbolic representations when they arose in the course of the interviews and systematically document them. Finally, some participant demographics, stories, and descriptive information may pose risks to anonymity (Polit & Beck, 2010), and in some cases, generalizations were made on demographic items and one story that may allow identification of participant was withheld.

## **Conclusion**

Phenomenology provided the philosophical underpinnings and the methodologic framework for this study. The author executed the study according to the procedure. No amendments in the IRB or alterations in the interview processes were required. Data were analyzed using Colaizzi's methodology. There were no breaks in the audit trail, safety precautions for control of records were maintained, and rigor via phenomenological approaches was achieved. The next chapter discusses the 'results' obtained, analysis and findings.

*We [used to] talk about our love, and talked about our closeness,  
and talked about our blessing and kept talking about it...*

*and I guess now we are... just... we're living it.* —Participant 001a

## **Chapter Four: Findings**

### **Introduction to Study Outcomes**

The lexicon of phenomenology is important, hence the use of *findings* or *discoveries* rather than the positivistic term, *results*. The phenomenon under scrutiny is the narrative of a spouse caregivers' relationship closeness with a focus on the care-recipient's cognitive impairment and neuropsychiatric symptoms. Using a Colaizzi-ian language and reflective methodology, the outcomes of this phenomenological study are 1) the author's individual phenomenological reflection that illustrated the researcher's discovered fundamental structure of the phenomenon, 2) the stories of participants in the phenomenal study that exhaustively and empirically described the phenomenon and contributed to the subsequent perspectival fundamental structure, and finally 3) the discovery of the comprehensive fundamental structure that gives voice to the existential meaning of the phenomenon. This chapter focuses on the second outcome, the phenomenal study, and its resulting perspectival fundamental structure. Chapter Five will share the discovered comprehensive fundamental structure and elucidate its meaning.

### **Participants**

A purposive sample of 16 dementia spouse caregivers participated in the research study. Postcards and flyers facilitated recruitment. Two participants replied with mailed postcards originally placed in senior citizen lobbies; one mailed the postcard and one called for information using the number noted on the postcard. Nineteen participants responded from distributed flyers.



Eight potential participants emailed and nine telephoned directly for information about the study. Five participants were excluded from the study based on consent or inclusion criteria. Two participants declined to consent; one participant was an unmarried caregiver, and two participants' spouses were in long-term care. Inclusion criteria were met, meaning the sixteen prospective participants were English-speaking, dementia spouse caregivers living in Southeast Connecticut and they co-resided with a >65-year-old spouse diagnosed with dementia. All caregivers possessed the capacity to consent and provided written signatures per protocol.

The caregivers self-identified as spouses who had a husband (68%), or wife (32%) diagnosed with dementia. The male caregivers' age ranged from 65-80; the female caregivers ranged from 65-86. The male care-recipients age ranged from 67-88; the female care-recipients ranged from 67-85. For 11 participants, this was their first and only marriage. The caregivers were dealing with a variety of dementia typology for approximately one to four years. They lived in homes in the community, were well educated, and apart from one, described the family finances as average or above-average. The sample was entirely Caucasian with higher than U.S. average education levels (see Table 6).

Table 6.  
*Demographic Characteristics of the Sample, N=16*

| Variable   | Spouse Caregiver<br>n=16 | Care-Recipient<br>n=16 |
|--|--------------------------|------------------------|
| <b>Gender</b>  |                          |                        |
| Female   | 11                       | 5                      |
| Male   | 5                        | 11                     |
| <b>Race white</b>  | 16                       | 16                     |
| <b>Age (average in years)</b>                                    | 74.5                     | 78                     |
| <b># of Marriages during lifetime</b>                            |                          |                        |
| one  | 11                       | 11                     |
| two  | 5                        | 4                      |
| three  | 0                        | 1                      |
| <b>Age when married to current spouse (average age in years)</b> | 29.75                    | 33                     |

|                                  |                        |      |   |
|----------------------------------|------------------------|------|---|
| <b># Years married</b>           |                        |      |   |
| (average number in years)        |                        | 45.3 |   |
| <b>Education</b>                 |                        |      |   |
|                                  | High School            | 5    | 4 |
|                                  | College                | 6    | 5 |
|                                  | Graduate/Post-Graduate | 5    | 7 |
| <b>Occupation</b>                |                        |      |   |
|                                  | Business               | 5    | 7 |
|                                  | Education              | 3    | 4 |
|                                  | Health/Science         | 4    | 4 |
|                                  | Homemaker              | 4    | 1 |
| <b>Dementia #years diagnosed</b> |                        |      |   |
|                                  | 1 year                 | 3    |   |
|                                  | 2 years                | 7    |   |
|                                  | 3 years                | 3    |   |
|                                  | 4 years                | 3    |   |

For each of the sixteen participants, stories were prompted using the identified open-ended question. Comments from the researcher were only to clarify a statement from the participant or ask for examples. The author did not steer the discussion. Digital technology captured the caregivers' response to the question; their recorded stories lasted from ten minutes to one hour and eleven minutes. The dialogal interviews were transcribed to Word documents. They yielded 435 significant statements or approximately 27 statements per participant. Representative significant statements and their formulated meanings were eidetically reduced (see Appendix I for early NVIVO *ps* data control and organization of empirical data). After Empirical Phenomenological Reflection, five prominent themes, and three of those major themes subsumed ten meaningful subthemes. The themes emerged as the critical elements of the caregivers' perception of the phenomenon.

### Field Notes

Recording and transcription of participants' interview captured a diversity of feelings. Many of the emotional, humor-filled hoots and silent pauses were easily recognized on the recording but provoked a challenge for the researcher to equitably transcribe that exclamation,

sensation, moment of despair and cacophony or musicality, in documentation and the written record. The author attempted to reflect emotions with the use of ellipses and dashes, as well as notations of laughter, whispering, tearfulness and onomatopoeia. Nonverbal notations included hands in the air, eyes rolling, and other physical display of action (slicing, pounding on the table, grabbing and “duh” hit to the temple). Field notes included observation of home life, and more circumspect journaling if the author observed the couple together, and later, entered a personal narrative and general impression of the participant and the encounter.

From field notes, some examples of participants saying more than their literal words:

*We do have a problem with (whisper) incontinence.*

*And then he looks at me and he sort of begins to laugh and then I’m done with it, I’m ridiculous (laughter!). That’s right. He never refers to it. I call it loud impatience... (guffaw laughter!).*

*He understands and sometimes he is upset because you baby him, he can’t, he can’t [do for himself] ... (tearful)... because he wants his dignity. And so, you have to realize that...you have to realize that! So, that’s how we proceed. .... (profound silence).*

*And so, the bond of being really close seems to be disappearing a little, (silence)— all the time. (prolonged pause, eyes welled up; recorder turned off for time to recompose).*

Sometimes the way people talked allowed emphasis not only with volume, i.e.: louder, but spouse participants used tone, repeated important thoughts, words and phrases, and used physical motions:

*When at the end of three accidents and then when he drove right through the garage and out the back (loud)...I was with him! (louder) And we had to see a neurologist and the*

*neurologist did all kinds of tests and that said...ooooof! the disappointment was there! Tsktsk (shaking head side-to-side).*

*And with the children talking about things about the grandchildren and now that isn't there. That isn't there.*

*It's a lot like having children again, the planning that you have to do and organization, yes, absolutely. Yes, absolutely it is!*

*...you know we laugh and giggle and did everything, it's fine and then, boom! (loud; hand comes down). It's just about that sudden and that abrupt and that unpleasant.... Very unpleasant.*

During the interview in one particular participant's home, the spouse asked the author to join her in another room; it was necessary for the wife and she desired validation in some way by allowing the researcher to see her husband's plaque. She said, *"He was president of the senior citizen's board for a number of years. They gave him a certificate. Because they realized he was having some trouble I think. I have to show it to you. It's on the wall. I put it in... I framed it. This is it."*

Sometimes the sighs, the silence, the pauses and the slow conversations reflected powerful and personal thoughts. There was intentionality when one participant remarked, *"I feel really alone. Even with him in the room, I'm alone. (pause) It's almost like you are watching it. (pause) I'm watching my husband go away from me. (prolonged pause).* Another spouse also related, *"...he looks up and he knows it's me (sigh—deep breath, and smile)—that's good.*

## **Discoveries**

The relationship closeness as recorded by dementia spouse caregivers was complex. They described it as a lifestyle of living and knowing, within the framework of the terms relationship

and closeness. As opposed to traditional bonding statements about intimacy and affection, the caregivers had an expanded RC life experience with dementia. The dementia gave oxygen to a larger relationship (metaphorically, greater than the sum of the two). They perceived and discussed it as good, bad and tolerable. The rest of this chapter illustrates the richness of the caregivers' stories allowing the foundation of fundamental descriptions, and with the author's imaginative listening and empirical reflection, communicates their perspectival fundamental description.

The findings of the phenomenal study are summarized in Table 7. and explained according to each theme. Empirical variations are explained, and the fundamental structure is revealed.

Table 7.

***Constituent Characteristics of the Phenomenon.  
Dementia Spouse Caregivers' Relationship Closeness:  
A Journey of Living and Knowing.***

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Theme 1. A history together

Theme 2. I see the dementia

- a. We have a dementia story
- b. Naming the symptoms
- c. Knowing the disease

Theme 3. I feel the dementia

- a. Loss and hurt
- b. Sounds and silence
- c. Cherished moments

Theme 4. I respond to the dementia

- a. Advocacy
- b. A compassionate love
- c. Imperfect caregiving
- d. Balancing the scales

Theme 5. A future together

---

The overarching concept of change over time, travel and journey was described by all caregivers. The author will allude to the metaphor of the dementia journey throughout this discussion and present it as a story with a prequel, characters, plot, conflict and denouement. The pithiest comment by a participant was, “... *you know, we keep going. I think that’s what you have to do, you have to keep going, like a journey yeah, and that’s part of who I am, and I’m a person who just keeps going anyway.*” All the caregivers expressed their relationship in timelines, uniquely identifying the past, present, and future. One participant emphatically parsed and condensed the temporal nature of dementia, “*The past is very present a lot of times.... The present, sometimes.... The future, forget it!*” Other participants reflected on discrete past, present and future characterizations of spouse care-recipient, RC, the nature of the disease, and CI-NPS as illustrated:

- |            |  |
|------------|--|
| Past       | 1. <i>He was president of the senior citizen’s board for a number of years.</i>                |
|            | 2. <i>She was a brilliant woman. She was so much smarter than me!</i>                          |
| Present    | 1. <i>So, it's difficult. It really is difficult. Some days, it's like, oh, why? you know?</i> |
|            | 2. <i>Well, there are days when I don’t feel like he’s my husband.</i>                         |
|            | 3. <i>Just talking with him it’s hard these days.</i>  |
| And future | 1. <i>I don’t know what to expect. I don’t know what the future is.</i>                        |

The caregivers also identified another temporal construct expressed as the capricious nature of the dementia itself. The disease varied from moment to moment and day to day. Dementia, they described, was and will be a progressive, stage associated variable with an unpredictable nature. It will have an unknown future with mysterious symptoms yet to come—. “*It’s the apathy I think is probably the most difficult thing to deal with because he was always very engaged and we did a lot of stuff. And he’s just not interested in a lot of things anymore, but*

*we keep going, like, he used to golf in the men's league and he was a really avid golfer; now he will only golf with me. So, just, it's an evolution apparently.” And, “...so the bond of being really close seems to be disappearing a little, – all the time.” And, “Part of me wants to know what's ahead and part of me doesn't. The thought of having to clean him up if he has accidents..., when he has accidents, [it] just breaks my heart. Plus, I just don't look forward to it.”*

For parsimony, the following titled themes are the participants' perspectival fundamental description that emerged after an empiric reduction. The phenomenal study was the empiric data set. The author dwelled with dialogal captions. The emergent meaningful statements are depicted individually to illustrate each theme as a fundamental description of the phenomenon, but in the end, reflectively reduced to the phenomenal structure. Appendix J documents a sample of significant statements and formulated meanings. Although each theme was supported by every caregiver, a portion of the strongest and most profound statements are shared. After each theme and subtheme, a description and recollection is provided.

The essential constituents of the relationship closeness and the spouse caregiver dementia journey are described in the following pages. The author will portray each of the themes to illustrate the perspectival fundamental description. The constituents of the relationship closeness and the spouse caregiver dementia journey are shared by all participants, i.e.: essential, or having an essence as part of the phenomenon.

### **Theme 1: A History Together**

Every spouse caregiver interviewed spoke in a very descriptive, reminiscent and colorful way about their husband or wife who now has dementia, or at a minimum, the way the couple was, or *used to be*, together. The couple's history was illustrated as a personal biography, their wedding, the business, or early marriage with young children, and shared activities. The stories

were significant but in the past tense. Many of the participants clearly enjoyed telling the happy stories of how they met, “*We’ve been married for 62 years. We met in high school.*” And, “*We met way back in high school, I pursued him, he did not. I was only 15 when I first met him and we were – it was a square dance.*” One couple met later in life, but still had a history, “*We both had had spouses and lost them and so we did not like being alone very much and so when we just were kind of clicking, and in love, and it felt right.*” These couples had a relationship, distinct from closeness, in that they did not know each other well. Early on in their marriages, there was mutual attraction and sometimes pragmatism, convenience or luck.

The caregivers also took delight in recounting the mutuality of the relationship and shared activities. One spouse reminisced, “*We did an awful lot with the kids.*” Another said, “*He was in the choir and I was in the choir because of him. And that was a connection.*” And a third remarked, “*I always was there with him, by watching him in the [marathon] races.*” Athleticism, physical activity and hobbies were an important part of couplehood where each spouse could be autonomous, yet join together for mutual support.

Participants also spoke of “the way they were” or things they used to do together. They bemoaned how different it was compared to the present. For example, “*It’s funny to look at pictures and someone will say look at that, look at your dad when you did this, or we talk about things that he did as a younger married person and of course it was so different.*”

Reminiscence of couplehood was an important part of the caregiver’s storytelling. One co-researcher described how she viewed her, and her husband’s maturity at the beginning of couplehood, “*Well, we met when we were young in age, but we were old enough in life experience. He had been to Vietnam and back. I had been working as nurse living on my own.*” And two participants described a depth of conversation that was prized in their earlier



relationship, *“There was a real heartfelt intimacy. He’d understand me, understand where I was coming from, not just put up with why I did this or why I made this decision, but whether he agreed with me or not, at least have an understanding of it and vice-versa.”* And, *“...we’d just talk [every day] about [all of the] things that we did.”* The relationship was based on feelings of trust, open dialog and commitment. Meta cognition, specifically empathy and understanding, was an assumption to maintain the relationship. Interdependence framed the marriages.

As the antithesis to reminiscence, one husband remarked that the dementia disease seemed to cancel out your past, *“... and she was the queen [Christmas] wreath-maker for the garden club. She was the historian at \_\_\_\_\_ (a local town community). She was, you know, she had a lot of public activities and a lot of friends, lunch club and stitch & bitch (sewing), I don’t know. She was involved in a lot of stuff. She worked with me in the business and her background was – all right, she was very accomplished and intelligent. And now, ... (shakes head side-to-side connoting no). It’s gone.”* This comment clearly described the couple’s history and the comparative focus, then and now, recounted by caregivers.

Participants were not specifically asked about the past, but it arose independently as an important part of relationship closeness. Their biography was important and it framed RC between the husband and wife. This section of the interview was comfortable, and participants had an ease with sharing narratives from bygone years. The characters of this study were introduced by reminiscing; it was, in effect, a prequel to RC now with dementia. The appearance of dementia disease was the next major theme. The interview moved naturally into a comparative focus of the present dementia living with the past. Caregivers used their biographical history and dementia’s current domino effects to see and feel the dementia, and their hearts and minds to know the dementia.

## Theme 2a. I See the Dementia: We Have a Dementia Story

The caregivers' story incorporates the *ah-ha* moment when dementia symptoms are undeniable, as in this narrative about a family member's confrontation with an unusual CI-NPS symptom, *"Her oldest daughter... usually comes on Sunday morning at 8:30 which allows me to go to church. Last Sunday, I got back [she] was panicking, 'mommy didn't know me.' [She] left at 10:00 o'clock and went home. We met her and her husband at one o'clock for lunch at a restaurant, [My wife-the care-recipient said] 'hi [daughter's name], nice to see you' and everything – back to the normal."* It was the first time the care-recipient had demonstrated psychotic symptoms to the daughter; the daughter was frightened by the, agitation delusions and agnosia, an inability to recognize someone or something. The spouse caregiver explained in the interview how upset the daughter was during that encounter and how confused she was at the following social meal at a restaurant. Things went back to a quasi-normal atmosphere, but the daughter spoke of this episode multiple times over the year. The husband caregiver had been dealing with CI-NPS and the psychosis was now exhibited beyond just the dyad. It was confirming that his spouse was not intentionally misidentifying only him. Vivid realization occurred; dementia was present and was noted by people outside the family as well.

However, some couples identified an intensity point when the spouse caregiver recognized the diagnosis of dementia through pivotal and dramatic stories. A wife said, *"...when at the end of three accidents and then when he drove right through the garage and out the back, I was with him."* And, *"We had to call Triple A at 10:30 at night; we went out for dinner at friends and we were still an hour away; we hit curbing and I knew something was wrong with the tires and we were lost and I couldn't make out the directions. And we came up on a police station, I went in to get help. The tire was shredded."* One caregiver spouse recognized her

husband had confusion, fatigue and weakness, “[he was sick] I took him to the hospital the next day...So, what happened at the hospital was just a lot of tests, four hours in the big test...—the CAT scan, EKG and everything and it boiled down to dehydration and dementia.” She was not expecting a dementia diagnosis. These seminal stories recalled frightening experiences as an initiation to dementia diagnosis. There was also realization of how dementia physically changed the dyad’s lifestyle.

Another crucial episode of health care related to diagnosis found a spouse wanting reassurance; she felt the inability to comprehend dementia disease, “*You know when we went to the doctor this last time we got the diagnosis. I said to the doctor, can I tape-record our conversation in here? because they throw a lot of words and everything is fast in a doctor’s office. She said no, they wouldn’t let me do that; because I thought then I could listen to it, my daughter could listen to it, we could listen to it again and again. But she said no that’s not what we do. (pause) I don’t know why.*” The caregiver explained during the interview that she just wanted to understand what was happening and that her daughter had medical background and could translate the relevant information in a way the participant could grasp and comprehend at a simple level. This event, she said, made a huge negative impact on her future expectations with that doctor’s office. The event of delivering a dementia diagnosis is a milestone in the dementia journey.

Early symptoms of memory and self-neglect were insidious for one caregiver, and she finally realized her husband was failing, “*He really wasn’t taking care of himself in the sense that he wasn’t taking his medication correctly.*” Memory and neglect were identified as the precipitating symptoms.

The spouse caregivers' dementia stories also include looking back at symptoms that the spouse caregiver now knows to be CI-NPS, *"I started to see him change his dementia probably in his late 50s. But it wasn't until he was in his 60s that I really saw the memory issues His mother had Alzheimer's. So, I can't say that I was always watching for it, but it was always something in the back of our minds. And I can see now looking back that some of the things that he did at that time were some signs of some cognitive impairment."* Or, *"And the staring off into space, which ... then, I would just get cross at him. Why aren't you paying attention? And now of course I could kick myself."*

The dementia story is told in many ways, but once the disease is diagnosed, recognized, or confronted, the setting of our story has been identified. It is called exposition in the parts of a story. The symptomatology and essence of dementia emerge in the next theme as the plot thickens.

### **Theme 2b. I See the Dementia: Naming the Symptoms**

Many caregivers identified memory loss, speech and language changes and inability to recognize someone for whom they are very close, e.g.: spouse's name, who children are, or the misidentification of spouse as mother, father, sister or brother. Caregivers' recounted some symptoms that interfere with an integral element of the relationship, but now they say it must be accepted, albeit with frustration. Some caregivers were at the beginning of the disease, *"He'll forget names of people that were distant acquaintances, but he does remember everyone's [the family] name. So, he's still, you know, we're still in a good place there."* Or, *"With the disease, there is a lot of repetition of decisions, like, what are we going to have for dinner."* Cognitive impairment symptom of amnesia was recognized. Memory loss was identified as a problem in the maintenance of instrumental and activities of daily living

Two participants noted that the symptomatology of speech and language loss was evident to friends and family, *“he talks very easily and readily to them even though sometimes what he says doesn’t make sense.”* Also, *“And with the children talking about things about the grandchildren and now that isn’t there. That isn’t there. Oh, my son’s oldest son was very ill—you know, we really couldn’t talk about it with him (dementia spouse) because he just would take some of it in and then he’d forget it, you know?”*

Moreover, some caregivers were dealing with troubling NPS or many CI-NPS. One caregiver said, *“So, it’s difficult. It really is difficult. Some days, it’s like, oh, why, you know, why and he gets angry and then he gets sad and then he gets depressed, and then he’ll laugh...”* Another spouse recognized hoarding for a dementia symptom, *“The hoarding is a big thing. Every time he wants to go out, he wants to buy something and that gets me worked up. You know, you don’t need another shirt, you don’t need another jacket, you know, he’s got bins and bins and bins of clothes that he purchased, you know, not opened and never used.”* Confusion, circadian rhythm loss and poor problem solving disrupted schedules and plans, *“You know, he wakes up. Even now if he takes a nap sometimes he gets up and he thinks it’s the next day.”* A spouse admitted the agitation in her husband, *“... sometimes he is very, very angry.... Sometimes.”* Mood symptoms and aberrant motor movements were frequent. Loss of circadian rhythms and NPS symptoms of mood swings, hyper-reactivity, and labile depression and euphoria were recognized.

The dementia symptoms were very real to spouse caregivers. The participants remarked how tedious, frustrating and unpredictable they are. A participant illustrated the repetition and tedium, *“We have the day events on the calendar, but it’s the same, what are we doing today? Do I have a hair appointment today? what time is my appointment? When are, we going? Then*

*she is ready an hour before we have to go.” Another clearly stated the frustration, “[we can be visiting friends and] he’ll go upstairs when we’re in their house and take his clothes off and go to bed.” And finally, a spouse talked about the randomness of it all, “He blows up once in a while yes. Yeah. It’s unpredictable. He can get very stubborn. He gets stubborn.”*

It is a challenge every day. One spouse summarized in a sensitive way, “*So, just every day, it’s a challenge of whatever that day has in store for him.*” Dementia’s conundrum was that the care-recipient had the disease and diagnosis, but it was caregiving spouses who internalized the symptoms, thus co-opting reactive moods, anxiety and tension.

Symptoms were discussed by participants in a concrete way, black and white, right and wrong and good or bad. However, the co-researchers also tried to abstractly understand where their spouse was, and what was happening from their point of view. The next theme describes what caregivers know, and what they do not know about dementia, as well as the desire to know more vs. the fear of knowing too much.

### **Theme 2c. I See the Dementia: Knowing the Disease**

The co-researchers all identified a way of knowing the disease regarding their personal education, expectations, and/or preparation. They related that they knew something of the disease, “*On the surface, it’s tough the way everyone said it would be.*” Moreover, they sought help to know the disease, “*...now and then, I’ll call her [a support group member] and we’ll talk, and she’ll tell me how I had helped her and she has helped me, one on one, one on one. I think that is a great that we can do that. She gave me suggestions how to help with losing his glasses. She said, look somewhere where they just fit because that is what [my husband] would do all the time; she said, we found his wallet in the Kleenex box because it just fit inside. I said,*

*Oh, that's very interesting. And so, I have this little table with a small drawer in it; and sure enough, that is where the [glass] case was."*

Equally, they identified a deficit in their learning and knowledge about the dementia disease, *"And their [people with dementia] moments, and I don't know what percentage of the time these moments [normal behavior] fail."* And, *"There is a part of me that's a little scared [of the symptoms of the disease]."* And lastly, *"And I haven't quite gotten to the point in my life where I completely understand the [dementia] sickness and the symptoms."* There was some knowledge of the dementia as a disease, but there was room to know more.

Some spouse caregivers processed the notion of dementia disease, and described knowing their spouse had dementia because behaviors changed and their care-recipients became more dependent, *"Yeah, I bathe her, feed her, dress her, and undress her."* Alternatively, *"It's [dementia has] made me make decisions on my [own]—on our future together."* Some caregivers knew the dementia was part of their relationship when care-recipients needed to be close in physical proximity, *"I notice there is a little sense when he is not right here in our home, that he is sort of looking to be sure I'm not too far away."* And on the contrary, when spouses were intentionally putting distance between themselves and the care-recipients, *"...these signs that you don't pick up [dementia symptom masquerading as legitimate feelings], and so that was distancing me [from him]."* Recognition of the severe dementia effects on behavior, signified the spouse was taking a more objective look at dyadic interpersonal relationship and interdependence.

The spouses knew the dementia entered their life at a salient moment when they described their care-recipient spouse was becoming lost, fading or invisible, or evolving into another person that they did not know; *"I'm living with this other person. It's not really my*

*husband.” And, “Your partner is gone— physically, they’re there, but it’s just the shell of the person that you remembered.” Also, “I keep saying to myself, this is the disease. It is the disease. It is not him.”* Another husband caregiver stated, *“And I think I’ve gotten pretty good at changing the way I look at things... to be consistent within this new batch of behaviors... and the ‘new version’ of [my wife].”* Caregivers began to understand how the disease altered RC elements of intention, response and social boundaries.

Still, other caregivers placed themselves in the mind of their spouse to relate how they must be feeling and knowing the dementia disease, and in some cases the care-recipient was unaware of the disease and symptoms. One caregiver identified anosognosia and remarked, *“You know, he doesn’t have dementia in his mind, you know, so that’s the hard part.”* One more reflected, *“You know, he doesn’t understand what his issues have been.”* And, another spouse said, *“I think he doesn’t verbalize many things, and I am not sure if he quite notices the difference. He doesn’t talk, so I don’t know what it is like to be him anymore.”* This empathy was verbalized by half of the spouse caregivers. Finally, a wife caregiver whispered, *“When he was describing a house shrinking and being inside another of our houses. I said, God it must be so awful to be so confused.”* That caregiver illustrated her husband might know he had the disease and she described it as a powerful metaphor of matryoshka houses. However, overall, caregivers realized that with this dementia disease, they could never be sure of what degree of insight their spouse retained concerning the dementia, *“...the forgetfulness almost like he doesn’t really forget I am here, but there is that sense that... he sort-of does.”* Or, *“And of course, you remember these things happen, did she remember? I don’t think so.”*

In summary, the caregivers identified that sometimes they knew about the disease and what to expect, and sometimes not. Some desired to learn more about the disease and others had



some reluctance. The caregivers tried to understand the disease from their spouse care-recipient's point of view but were tentative and uncertain. And finally, in knowing the disease, they found they did not always know this *new* spouse who had dementia. There is more information detailed in the empiric variations of *knowing the disease* in a later section. The next predominate theme continues with a developed sensory response by the caregiver: feeling the disease through loss and hurt, sounds and silence and cherished moments.

### **Theme 3a. I Feel the Dementia: Loss and Hurt**

There was a visceral response to dementia disease that caregivers expressed. It was presented in a variety of ways, but the message was that this disease hurt. Hurt and pain was related to loss in many instances. Loss was conveyed realistically and concretely by symptomatology associated with dementia. But more than that, it was through non-verbal communication, that caregivers shared the painful feelings. Field notes often reflected pregnant pauses, eyes tearing or welling-up, enormous sighs and shaking heads. On one occasion, the researcher asked to clarify what the lateral head shaking meant, and the husband's response was, *"It's no good; it's gone; I can't get her back."*

Three spouses became tearful and quiet when describing the loss of a partner within their marriage and in the face of dementia. For one spouse it was temporarily necessary to end the interview. She commented, *"And so, the bond of being really close seems to be disappearing a little, (silence)– all the time. (prolonged pause, eyes welled up; recorder turned off for time to recompose)."* Other variations of spouses describing their loss include, *"I feel really alone. Even with him in the room, I'm alone."* And, *"It is a sense of his not really connecting; [There is] the vagueness on his part."* There was recognition of loss of personhood and the changes in the typical expected relationship of husband. Caregivers were watchful and recounted observations

of verbal and non-verbal behaviors of their spouse with dementia. The notable loss of executive ability, interdependence and shared decision making, was dramatic and keenly internalized by caregivers.

One spouse caregiver recollected a restaurant fiasco in which his wife, decompensated. He called it her melting down. “...*the first time it happened, one of her grandsons, like, the poor kid was horrified, the look on his face. They don’t understand. I mean, she just loses it, you know.*” He continued to explain his wife with dementia “lost it” in a very literal sense, i.e.: loss of emotional regulation and psychotic expression. But the grandson could not fathom what was happening, and the caregiver described he was figuratively losing his grandmother too. Another spouse described losing her husband, but in this admission, she was also saying there was a loss for the children too, as their father, “*It is not [him]. And I think it’s difficult sometimes to explain that especially to my children because they think that I’m still living with their dad. And many times, he’s not [their dad].*” The expectation of being a husband and father has altered in a diminutive way for the caregiver spouse, but children still assumed the wholeness of “dad.”

Losses of memory, ability, and connection were described by spouse caregivers, “*And of course, you remember these things happen, did she remember? I don’t think so.*” And, “... *the hardest thing is not having conversations with him and not being able to bond that way. I think he’s not there sometimes. He’s just not there.*” There was a loss of mutual shared activities in the construct of dementia’s amnesia. Other losses of activities of daily living, cognition and functional disability are described below.

*I mean, you're doing everything for them. Yeah, I bathe her, feed her, dress her, and undress her.*

*He really, really loved to drive.*

*I remember this distinctly, oh I know, I started play Bridge and I started to really enjoy it, ...I was going to get good at it and he wasn't, you know. But I remember trying to teach him when I thought, what is the matter with him? I couldn't teach him. I couldn't get him to remember the counts of the ace, the king, the queen, the jack, I mean it's like he kept losing that.*

*With the COPD going on, lifestyle changed a lot because she couldn't walk anywhere. I mean, you know, I get to drop her at the restaurant door. You go park the car and come back and you pick her up. She's just, she couldn't walk. But then she just refused to use the wheelchair. Not even a cane. She was adamant. And now you have to hold her hand because she's frail.*

*The incontinence is painful. yeah, I mean it's such a backward step. It's just part of the scene [now].*

*As he got older, he was less able to physically perform, but he still pleased me. He would do something else, or we would find some intimacy in other ways.*

Loss was described as the forfeiture of spouse, parent and grandparent in addition to their reflective roles. Loss was also described by dementia's primary symptom influence causing physical and cognitive disabilities. And finally, loss was viewed as no longer being able to do shared activities. One spouse caregiver discussed dinner, *"And the meals are not what they used to be. Sometimes he doesn't want to eat. I find this a lot that in the evening that he wants to eat earlier and earlier. Or, he'll say he's not eating. He'll say, 'I'm fine, I'm not going to eat.'"* And a caregiver related a loss to not entering assisted living soon enough, *"And I'm sorry we didn't come a year sooner. He would have made more connections."*

The next subtheme following loss and hurt is sounds and silence. Communication whether by loud, raucous dementia behaviors; nonsensical, inarticulate or lack of conversations or the quiet in the heart of the caregiver who no longer has a continuous connection to the care-recipient in a high metacognition plain declared itself as a barrier to relationship closeness.

### **Theme 3b. I Feel the Dementia: Sounds and Silence**

Caregivers described their relationship within the framework of talking, interacting and exchange of information and ideas. The interviews demonstrated that for many caregivers there was a significant silence related to the dementia and they said it was a sad part of the disease. For example,

*...he doesn't verbalize many things He doesn't talk.*

*...but just an emptiness in him that he almost he sits there and just watches TV and he really, really is just captivated by it.*

*...and [we used to have] so much to talk about. You know, but the silence is easy now.*

*You know, talk and don't talk and listen and yeah, it's comfortable, yeah.*

But caregivers also describe loudness as if the volume had been turned up or there was an unsocial edge to the talk with swears or expletives.

*...he can get loud and defiant.*

*Talking sometimes is difficult. There's nothing to say, you know. It's quiet. As long as, you know, you're not being cursed (she described her husband started using four letter words in conversation).*

*She goes off, starts screaming, help me, get the police, he's trying to kill me.*

Conversation was sometimes physically difficult, and arduous, or the attention and desire from the care-recipient was not present. It sometimes took a lot of energy from the caregiver, as

described by this spouse, *“I think it could be hard to say exactly how I feel, but I think I don’t talk to him as much now because he can’t understand me, he can’t understand what I say, he makes me repeat three times. And so, I get to the point where I think why should I talk on simple things like common things a husband and wife would usually make that aren’t necessary.”* And, *“Maybe his inability to hear because his hearing is terrible. He does have hearing aids. I can be sitting right next to him, speaking right into his ear and if he’s not focused, he doesn’t hear what I’ve said. So, it’s part of the focusing and the hearing. I don’t understand that. I’m not sure he understands it. He just isn’t there.”* Dementia caused disruption of the speech and emotion center typified by amnesia and aphasia, but conversely the language could be loud and boisterous, in context as well as psychotic. Anomia, aphasia and psychomotor slowing provoked a cascade of speech pathology culminating in the loss of meaningful discussions usually prized in the marital dyad.

This wife explained the disjointed aphasic communication, *“He was trying to tell me something and then... He gets a little frustrated at not being able to tell you. I just say, ‘Is it this?’ And then I go over I say, ‘We’ll find out later what it is.’”* Another wife described the problem with dementia’s inattention, *“he just can’t positively turn his head to hear what I am saying.”* Spouse caregivers adjusted their verbal interactions for convenience and to decrease anxiety.

Similarly, spouses identified there was a loss of higher metacognition, where the couple used to be able to read, empathize and grasp the conversation. They said that was no longer evident. One caregiver thought, *“Just talking with him it’s hard these days; definitely different from before. Because we use to talk and joke and share things and all, but now I tell myself don’t say it unless it’s important because he is only going to want to know what I said and by the time*

*it's repeated three times it doesn't make sense to him."* A husband caregiver remarked, *"We used to have very good conversations That's something I really miss. ...she's at the point now where the conversations have to be somewhat simple."* Dementia caused frontal and temporal injury that coordinate complex thought and understanding which allows meta-cognition. Inattentiveness and psychomotor slowing prohibited multitasking, the interpretation of abstract ideas and the ability to forecast consequences.

Caregivers persisted in conversation to their spouse care-recipients despite the aphasia, *"Conversation is minimal, just not a lot of conversation because he can't remember a lot, and much of our conversation is me answering questions, but we try to have, you know, when the news is on, I try to converse about that. And I'd say most of our conversation is related to our family. We're lucky we have our family around us."* Another husband also continued conversation and stimulation, *"So, we can talk about the news; we watch the news all the time, and we can talk about the political things and public events that are going on. A lot of times, what I'll do is, I will – she can't read the newspaper so I read the newspaper to her and we'll talk about things but we can't get in depth because her level of comprehension is not good."* Sometimes there was a juxtaposition of speaking for the sake of sound.

One spouse described the repetitive conversation of his wife wanting to go home. He said no matter what he tried to do or say or explain, he couldn't understand where she wanted to go. *"It had to be around 2:00 or 3:00 in the afternoon, I want to go home, I want to go home. But that, I want to go home, [we were on a boat] ...was it, 'I want to come back to the dock?' I want to go home. Where is home? I don't know, I want to go home."* He said the looped conversation was frustrating and nonsensical to him.

The silence and sound was a two-way street, *“that’s our conversation now; there is a silence because he will just have nothing to say, then I just have nothing more to say.”* The silence between a dementia couple was equally distributed. The care-recipient had aphasia and apathy, and caregiver gained no reciprocity or positive reinforcement with the one-side conversation; it was exhausting. The quiet could be satisfactory, merely tolerable, or painful. One spouse caregiver said she hesitated to talk about getting older and refrained from mentioning the dementia disease itself, *“We have never exactly talked about it because I felt so bad-like for him, and also, he was aging, and I figured it would be like him to say oh no don’t worry about that, but I think he either couldn’t put together in his mind now, or wouldn’t know what I meant.”*

Another wife explained that she alone knew what he wanted or felt, *“I always have to go with him. There’s no one else that knows how he feels sometimes.”* One more spouse shared they had their own language, *“[It’s] almost like reading his mind or connecting the dots; I don’t know the insight you have to explain what he’s trying to say or do.”* One caregiver said she was okay with the silence because her husband responds non-verbally, *“I tell him very often I love you. Yes, I love you, and then his eyes light up. It’s a good feeling he gets.”* A new dementia language was formed.

In summary, the caregivers described absence and loudness of interactions, the physicality of speech, and the change in the information received by the care-recipient. Some caregivers were content with the quiet, and some yearned for a deeper conversation. Caregivers still used speech, verbal and non-verbal to communicate, reassure and maintain the relationship closeness. All caregivers said in some way and to some degree, their ability to talk with the care-recipient was disrupted. Dementia caused psychomotor slowing and altered the level of

consciousness in that there was an extreme difficulty switching tasks. It could appear that a care-recipient is focused, but may in reality be in a semi-hypnotic state. It could be perceived as ignoring or disrespecting the spouse caregiver.

The next subtheme counters the discouraging loss and hurt, and sounds and silence. Many caregivers shared stories of kind and nurturing moments. It was described as a magic moment by a caregiver because the behavior came out of the blue and was so very like the spouse they knew pre-dementia.

### **Theme 3c. I Feel the Dementia: Cherished Moments**

Spouse caregivers described moments when they experienced uplift, for example enjoying a shared activity, *“We took that trip on the ferry with the memory group. Well it was really wonderful, and I’m glad we did it. Because it was different and we both enjoyed seeing everything. At first I was a little skeptical but in the end, you really enjoyed it. We need more of that.”* Alternative and new ways of incorporating mutual activities could be shared; a planned event was stimulating and distracting in a good way. Caregivers also used reminiscence and found joyful periods, *“And it can be wonderful. I feel good when he’ll ask me to go for a walk with him because I feel like we’re together; when we do that because we always – in our marriage, you know, in our dating, we always took a lot of walks.”* Reminiscence and re-creation of thoughtful times, behaviors and activities allowed caregivers to recapture old feeling of warmth.

Most uniquely, caregivers identified times, responses or behaviors from the care-recipient that the spouse caregivers remarked how much it was like they used to be. One spouse described it as cosmic karma, *“And so the closeness is sometimes there when I will be out here in the living room and he might be down in the spare room and he’ll come out and say, oh I just want to see if*



*you are still here and if you're okay. And I feel like that's my husband.*" Intimacy took different forms as dementia progressed and when there were moments when thinking and speech were clear and spot on, it reinforced the relationship closeness. Intimacy may take on a melancholy nature but is still seen as positive. Another caregiver illustrated what she called a return to temporary normalcy, *"And sometimes, he comes up with something funny and I'll think where did that come from?"* There were rhythms of behavior, not always predictable, when dementia behaviors were mitigated and there was an RC connection again.

Other caregivers, shared stories where there were streaks of the care-recipients' personality traits that did not seem to be going away. For example, *"He'll always say good morning to me, and put his hand on my shoulder as he's walking by. But I don't think that's any different than it has always been with us."* And, *"He still wants his sweets. He's always loved his sweets, that hasn't changed. Pie, pumpkin pie, pumpkin pie, he'll sit down and eat almost the whole pumpkin pie. I'll save the rest. He just loves his pumpkin pie, always did."*

Overall, the caregivers were able to relate stories that told of some days being better than others, or CI-NPS do not seem to be so bad. *"And then she will remember about the person, tell you everything about the time we did this, the time we did that, she will rattle right through it."* And, *"So, this is just a serious card that he gave me and thanked me for everything that I do. So, it was one of those moments for him to say, I know you do a lot for me."* A wife caregiver remarked upon a story her children told, *"Dad was more dad... Yeah. Not playing mean tricks [dementia symptoms]. I'll write it down, you know, today this happened and it was so good. It was such good feeling to have that. The feelings, that's hard to, .... what's it's really all about too."* Familiar rituals, like using muscle memory, allowed a re-creation of traditional affectionate

marriage behaviors (holding hands, anniversaries, gifts and the marriage bed). Those activities were reassuring to both spouse caregivers and care-recipients.

The next section is about how dementia spouse caregivers responded to the dementia. Their stories detailed their life at present and how they saw their relationship closeness responding to the dementia as an advocate, protector and custodial care provider.

#### **Theme 4a. I Respond to the Dementia: Advocacy**

Caregivers in their relationship closeness framework provided alternate roles in addition to wife or husband. The caregivers became aware of safety risks and the need for surveillance; One husband was worried if he should allow his wife to be alone while he continued his walk, *“And it’s challenging, we went on a long walk and she said, I’ll wait here for you and I don’t know whether I should wait with her, or continue on my own. Will she be OK on her own? I think about that now.”* Another spouse commented that she needed to be close to her husband when he was agitated, to prevent injury or escalation, *“I sense when it’s there. And that’s when I just have to be very observant and close.”* Dementia behaviors and lack of ability to identify consequences triggered the need for safety and surveillance; i.e.: to protect them from possible injury.

Contextually in that safety role, nurturance and affection prompted a desire to be extra careful.

Part of being an advocate meant some caregivers assumed a direct caregiving burden. They described these situations, *“We do have a problem with (whisper) incontinence.”* And, *“When you start taking care of someone, it is primary. It’s like taking care of a toddler. I mean, you’re doing everything for them. Yeah, I bathe her, feed her, dress her, and undress her.”*

Spouse caregivers also set daily limits in a new protective way because of the disease; and they defended care-recipients to shield them from stigma or insensitive others, *“You want to protect them. You don’t want them to get into a situation that will make them unhappy or hurt.”*

A protective and defensive strategy prevented the care-recipient from being in a situation that might be uncertain, with the full knowledge that persons with dementia will always possess feelings and desire for self-respect and dignity. More discussion of advocacy as a subtheme is provided in the later empirical variations section. The next subtheme of responding to the dementia addresses compassionate love.

#### **Theme 4b. I Respond to the Dementia: Compassionate Love**

All spouse caregivers recognized that there was a positive relationship closeness, but in some way parts had changed and other elements remained the same. Love was not always defined by sexual intimacy. All caregivers did not profess undying love, but they did have a warm compassionate feeling towards their spouse. It was described as overlapping actions and emotions: 1) physical intimacy, 2) a friendship, 3) companionship, 4) empathy, 5) kindness, and 6) consideration. Caregivers often told and showed their spouses of their love. They freely described their expressions in these excerpts.

*I will say, you know, many times even when he's upset, I'll say, you know what, I'm here for you and I love you*

*I tell him very often I love you. Yes, I love you.*

*She will come down and we will always kiss even before breakfast.*

*I [still] am now, —very! Closer than I've ever been, actually.*

*“There's a lot of hugging and a fair amount of joking. Yeah. And some yelling, not yelling, but some displeasure, maybe frustration. But, humor. Yeah. Like him saying, I got it right with, 'Well, aren't you the clever one.' Yeah, some humor. And he has this wonderful sense of humor that comes out of nowhere. You don't expect it at all. And he'll give a one liner that's just perfect for whatever is going on. And if anything, that's increased.”* The caregiver recognized

changes with her relationship, but the couple's history together was one of concessions and adaptability. The dementia disease was another chapter which requires flexibility and accommodation. Relationship closeness expanded with compassion, humor, and hugging (encircling with arms was first used in 16th century, an Old Norse word *hugga*, which meant to comfort).

Unfortunately, sometimes the offering of affection was rebuffed, *"Sometimes I definitely will still touch him or take his hand or talk to him nicely. Sometimes he accepts it and sometimes it's like don't touch me. So, I have to kind of gear where he is by watching his movements or whatever before I would say anything or do anything with him."* Or a new flexibility with intimacy was introduced, *"Sometimes, he mostly sleeps in the spare room, once in a while, you know sleep in our bedroom and I just let, whenever it happens happen, wherever he wants to be, he's comfortable, that's fine, that's fine. Sometimes, he'll start out at the spare room and he'll come into our bedroom at 4 o'clock in the morning."*

Empathy and unconditional love were described, *"...he does describe how he's feeling. Not in great detail but, and then I just feel so sad, I can't imagine."* And, *"I just feel so much compassion for him."* One caregiver described her desire to become more loving, *"So, I have to get over myself, feelings of being frustrated to go no further now, to be more loving."* The marriage bond and vows surpassed interdependence with a higher-level love than that which we equate with "affection."

Compassionate love was spread throughout the dialogs whether by overt language, demonstrative actions, or compassion and empathy. This was expressed by a wife, *"I will say, you know, many times even when he's upset, I'll say, you know what, I'm here for you and I love you. And sometimes it calms him a little bit."* "I'm here for you" in today's jargon means: I've

got you, or I've got your back. It encompasses a broad lexicon related to reciprocity, overarching care of all needs including finance and safety, or just being in the moment with mindfulness and no prerequisites. Like love, it is an open positive concept. One caregiver stressed that kindness was most important in this family disease, *"I almost think sometimes, that it's almost like a fate or something [as to what family gets this disease]. There needs to be patience. I think that this is about this whole world. If everybody could just be kind, it would be so nice. Just be kind."*

Compassionate love was further defined, *"[We've become] more like friends; the love has been a lot more unconditional. All of our closeness and physicality, and kissing before you leave every time, and when you come home every time, and just various times during the day, you know, and we just look at each other and say, 'it's time!' and have a big hug."* The adjective unconditional meant I will continue to love, under any circumstance, and no matter what happens. The caregiver identified the progression of the disease, a timeline of potentially changing events and the commitment which meant an altered lover-to-friends concept.

Finally, spouse caregivers could be proactive and intentional in their devotion, *"So, there are times when I think, oh he's just doing that to bug me or he's just not paying attention when he says 'why,' every time I say something; and I get like, come on. But then I realize, I step back and I say, okay well this is the dear man. We've been married for almost 50 years and we had a wonderful relationship up until this. So, I have to get over myself, feelings of being frustrated to go no further now, to be more loving."* Cognitive behavior therapy and problem solving principles were intuitively applied with the result redirecting the caregiver back to elemental love. She remembered and so recommitted to the love relationship.

The next subtheme concerns the relationship feelings of guilt and imperfection as a caregiver.

#### **Theme 4c. I Respond to the Dementia: Imperfect Caregiving**

The desire to be a better, not a perfect caregiver was shared by the spouses. All the spouses identified times when they could not be the good spouse and the good caregiver. There were limitations. They discussed it in terms of success and failure, *“Little reminders for her that the dish by the sink is, has pills in it and then, and I’d put them there carefully in the correct amounts and could she please take them and then, the next morning, I get up and the dish is full and I was unsuccessful.”* Dementia disease required a flexible caregiving approach to produce efficacy. The caregiver recognized some new strategies and identified the important things, but was still in a learning curve. Or, *“Oh yeah, because you know I would never be good enough [taking care of husband] in my own estimation. I know, I know, it’s just the way I am.”* One husband was convinced he was not a caretaker, *“One lady in our [support] group was, I forget her name, she has got the greatest sense of humor. Anyway, I said to her one day, I’m just not good at this and she said you’re hard on yourself; and I said no, no, no, no, no. I’m not hard on myself. I’m really not good at this. I’m not a caretaker. I have no patience.”*

And dementia caregivers looked for ways to keep them on-track to be a better caregiver. *“I always try to open and pull out that little statement that says that: He’s not giving you a hard time, he is having a hard time.”* Another spouse described the difficulty in caring for her husband, but how her determination would win the day, *“It’s taking its toll I know it. I don’t know how strong I am, but determined probably, my dad said I had more determination than, what he [used to] say, you’ve got more guts than brain sometimes.”*

Caregiving was ultimately described as imperfect by all sixteen participants, *“I’m sure I’m not unique in this (caregiver role) but I’m, given what I’ve gone through as it relates to my memory and my health, I’m less than whole too.”* Another wife admitted, *“I worry that I’m not a*

*good enough caretaker. That's it."* And other spouses described their caregiving as a work in progress, *"Our relationship... it's nowhere near as good as I think it ought to be."* And, *"I've adapted to having to do it [frustration at verbal repetition], but I haven't adapted as much as I want to."* And, *"I have to keep the frustration, you know, not only keep the frustration out of my voice, but keep it out of myself."* One spouse caregiver felt challenged with everyday living with dementia. She was able to see some of the helpful things she could do, but continued to worry about her efficacy overall, *"... I think that upsets me a little bit to know that, I try to get him do this, do that. It's kind of upsetting because I don't, sometimes, he just can't get that done and I feel almost like I'm failing because I'm not helping him you know? I just feel that way sometimes. I'm hoping all the time as I do the right thing and say the right thing and then sometimes I seem to be helpful but maybe there are somethings I should have done."*

The emotions caregivers had, were sometimes short, impatient and reactive, *"I try not to argue with her. But two days ago, she drank a bottle of wine. She drinks a bottle of wine every day or maybe one glass short of a full bottle which is way too much for her. And so, she woke up and was having trouble falling asleep and wanted more ... And I got kind of snarky with her because of that."* Another spouse identified anger with caregiving, *"...sometimes I get angry at a lot of things that happens."* Another spouse acknowledged impatience, *"At night I blowup and he stays calm. Isn't that the opposite? Well, because he takes a long time to go to bed and I want to get in bed and have the lights and the pills taken and the eye drops finished and it can take forever."* And a wife caregiver recognized her limitations, *"there aren't really too many things that push my buttons. I mean there are so many things, there are little foolish things, I think of, he won't get a haircut. He hasn't had a haircut or beard trim since March."* And this spouse

accepted where the anger was being directed, “... *but I’m not angry at him. I do get angry, but I’m not really angry at him. But some of the things he does, I know he can’t help it.*”

Spouse also had thoughts that caregiving was too much, “*So, and some days I don’t even want to have to deal with him because he’s confused and he’s agitated, and it’s just some days it’s just too much.*” And, “*I used to get really annoyed. My brother said you have the strength you can handle it, I’m having a hard time. You have the strength. One day, I said, I’m getting sick and tired of being the strong one. Sometimes I just want to fall apart.*” Other spouses have thoughts of escaping, “...*not that there hasn’t [sic] been times when I liked to just put the key in the door – and take off.*” And, “*Walk with me, he said. So, we look like a couple that have just had a spat, because he is way behind me and he’s got further and further behind... and I just want to keep moving.*” The spouse illustrated a metaphor for a desire to escape the demands, responsibilities, lifestyle and future, expected as a caregiver, and necessitated by dementia disease. Lastly, one spouse caregiver was able to have respite from her husband to regenerate, “*I can blow after weeks of being with him. I can’t do it. So, I got away and I get refreshed, and I come back and it’s a new day...not going to do that today. You know the first thing in my head is all the things I know I’m not supposed to say.*”

But in general, the caregivers talked about their skill and realized that they were doing the best they could. One spouse admitted, “*So, all these little wee things that fall on me, there are some days that it would help me [if I could] unload... to harp on him about something, then it’s like o boy, I just think not now. I know we’re all doing the best we can, him too.*”

The next subtheme completes the dementia spouse caregivers’ response to dementia. It is presented in the framework of how caregivers cope, how the relationship has changed, and where caregivers find alternatives and positive regard for the altered spousal relationship closeness.



#### **Theme 4d. I Respond to the Dementia: Balancing the Scales**

Caregivers were inextricably tied to their spouse care-recipient and they continued to be present in the family, the disease, and the caregiving. Spouses honed-in on ways to make living tolerable and strategies that helped make relationship closeness with their care-recipients better, or at least tolerable. There is more information detailed in the empiric variations of *balancing the scales* in a later section.

Sometimes rituals and behaviors the couple together used to do, and now continue to do, allowed a comfort and familiarity. One spouse explained the equilibrium, *“How would I describe this? We are almost going on habit of how we always are with each other, well I just call it home life, I call it home life. ...because we have both been retired and home together, there is a kind of routine to your days and so it’s kind of habitual... talked about our closeness and talked about our blessing and kept talking about it and I guess now we are just were living it.”* Or spouse caregivers took control of their life to maintain semblance, *“Right now, this is my world, and whatever I have to do to make things be smooth and calm and for me to keep my sanity, that’s what I do.”* The spouse caregiver maneuvered and acclimated to the change with a goal of peace. She thrived on control and the status quo in her dementia world. Again, status quo and familiarity were described by a spouse, *“I don’t add anything to complicate my life right now. It’s just too hard. For my own benefit, I need things to stay status quo.”* Dementia caregiving was very demanding and caregivers picked and choose what action was acceptable and what was dismissed or temporarily left behind.

Spouses also described how the scale was out of balance and out of kilter, *“That scale was, like, pronged down to the ground as far as I’m concerned because if I don’t do it, it doesn’t get done. I have to think about what we’re going to eat for dinner. I have to shop for it. I have to*

*put it away. I have to cook it, I have to clean it up, okay, just the day to day operation of having ... [to do everything] and being alone, you know, making more decisions yourself, you know."*

*And, "And even the simple things he used to do around the house, he doesn't do anymore. He says he'll do it, but it doesn't get done. So, that's what I think the hardest for a spouse to have to accept that that the couple is gone, and that we can't...(pause) – all of these decisions are mine."*

*One spouse talked of the weight of her husband, "his whole world revolves around me, follows me around, looks for me. He doesn't have a separate life from me. And that's what's so hard."*

*Coping was described to keep life in balance, "I actually have to keep charts, you know, so I can keep everything under control because things get away from you. When did I change the sheets? Because you know you say, oh I did it last week, but it was two weeks. So, you have to do those things." A husband described the routine for meals and medicines, "We always have dinner together. We always start supper with a grace. We've always had breakfast and lunch together usually. I mean, once in a while, if I'm going somewhere or I'm just, you know, wide awake and she's lingering over her shower, I will eat breakfast without her, but we'll still end up having coffee together, always fix lunch together. And I have a chart for medicines too. You know, she gets these in the morning one pill, then she gets these in the afternoon or bedtime and because otherwise you won't remember these things." Caregivers provided structure for the care-recipient including shared activities, "Making sure that I have a big calendar so that I can check the calendar every week to see what do we have to plan for this week? And then, it's every morning making sure that I don't forget something like the medications."*

*Caregivers adjusted their behaviors to deflect eruptions and keep the scale level, "I know enough not to get too hoisted up if there is something incorrect that's coming out from him. So yesterday I said we're turning the clocks back this weekend he said it's going to mean it's going*

*to be lighter longer. No just the opposite and he insisted. So, I thought just let it go because what's the point of, that's often something that I find people will do or try to correct him and we've get them to not do that."* Again, caregivers talked about the need for flexibility in themselves, *"Oh, you have to soften things instead of being so strict yes. Definitely you have to blur the edges a little bit. You have to because – (if you don't) then you won't survive. If you're fanatic; you know that would be the worst thing in the world. Thank goodness, I'm not that way myself. I don't get worried like, this isn't just so. I like balance, but I don't worry if it got a little dirty, you know?"*

One caregiving husband eloquently summarized that if the house and chaos are controlled, and the scale was balance, he found peace in himself, *"When there's peace in the realm, there is peace in my heart."* Another thrived on simplicity, *"Simple things, simple things! Like I said, sometimes it's like living with a stranger or living with two different people. One is the husband I know, and one is not. Sometimes, he mostly sleeps in the spare room... once in a while, you know [he'll] sleep in our bedroom, and I just let [it be], whenever it happens happen, wherever he wants to be, he's comfortable, that's fine, that's fine."* The caregiver's expectations were flexible and allowed room for the care-recipient to decide where to sleep, emphasizing her desire for him to be happy and content. She was willing to "move the furniture" if there was an acceptable outcome.

Caregivers had unique ways of keeping the relationship in balance by use of humor, spirituality, inviting others into the care circle (a tapestry of care) and the need for a caregiver's self-care, i.e.: maintenance of health and wellness. There is more information detailed in the empiric variations of balancing the scales in a following section. The next theme finds the

resolution of our story, the dementia spouse caregiver's journey and their relationship closeness facing the future. It is about the strength of caregivers, their RC and an uncertain future.

### **Theme 5: A Future Together**

Couples discussed and described their future in terms of being *together*. It was a sense that this was what I accepted in marriage and I accept what life deals; conversely it could also include not accepting the caregiver life. The future together described maintaining mutual living but with a separateness due to ambiguous grief, as well as single, due to custodial care. Although there was a component of husband and wife separateness whether living together or not, a continued connection persisted. The future together was also deliberated in terms of the *unknown*- the conception of what might happen was variable, extreme, too mystical or too far-off.

Some couples described togetherness abstractly, but with a vow or a will to stay together in the future, *"So, whatever [my wife] might become, that's what I took. It's what I signed up for."* And another said, *"I am lucky enough to be blessed, you know with a husband, and if that needs taking care of... that man now and later, that's kind of how I'm made."* One more spouse knowing she had the option of a memory unit on their assisted living campus still preferred her husband stay with her in their apartment, *"I think what proves our closeness, is I don't want to see him go over to the memory unit or nursing home; which I thought would be, — be easy at some time."* And a spouse described continuity, *"I keep doing what I'm doing, we'll get through it. I don't need, you know, a diamond tiara. I'm just, you know, I'm happy with the simple things. I'm not a high maintenance wife."*

Some caregivers also described conflict and strain in their relationship especially in light of what the future holds, A wife explained, *"You know I just want to get through it feeling like I*

*loved him. If a feeling of friendship is better than nothing..., but I can't connect with that anymore. You know, but I mean, it's still the commitment is there, and I don't feel like it's a ..., I don't feel like it's a duty I have to do."* And another spouse expressed her needs as the future goes forward, *"So, I don't forget who I am, you know, and address my needs. So, yeah, when they say, yeah, sickness and in health, this is one of those things you don't sign up for."* A husband added his frustration with challenges in caring for his wife. He acknowledged as the disease was progressing, he was not getting along with her- the care-recipient, *"She needs social – she wants social interaction even though she won't do anything to get it. I think she would benefit greatly from a memory care center where she got interaction but she won't go, and she won't go to adult day services. So, as a result, I'm getting a whole lot shorter with it than I used to be— I ever was. We never had fight or her going off on things. Now, it used to be she could make changes; now, you can't make a change which is something you allude to with her. It's very hard to get a change going on. I get more aggravated, then I get shorter and get more aggravated that just goes on and on and on."*

Spouses were practical and realistic as to when their care-recipient would need custodial care; it was evident in their future planning. Some couples desired to stay together, and reducing the caregiver's burden would allow that, *"And I told our son, I said, you know the time may be coming that we should have someone full time, full time."* The pragmatism was described by a wife, *"It's made me make decisions on my – on our future together. You know, I have no qualms about when it's time to put the house on the market and move into, you know, independent living facility or just an apartment, less stress for me."* And another spouse talked of the need for plans for both of them, caregiver and care-recipient, *"I'm very, very clear on where this headed and try to be mindful in this relationship to make sure we have our advanced care planning done, and*

*our wills done and all this stuff in place and make sure he's made those statements and this is what I want down the road and this is what I don't want. So, it's clear to me and anybody else who [becomes a caregiver] what's to come."*

The future was also described as an unknown, *"Part of me wants to know what's ahead and part of me doesn't."* And conversely a husband spouse remarked he knew where the future would end, *"The future, forget it! I say the future is: we [husband and wife] both go. We have my sister who is buried there already, and we have one grave stone, I'm sure her name is on it and so is mine, and we're all going to in the same spot. (hardy laughter)."*

A spouse acknowledged the need for a plan for her husband, if she the caregiver wasn't able to provide care, *"I'm 65. There's no saying that I'm not going to start to be forgetful too. So, I try and make sure that I'm – that if something ever happened to me, somebody would be able to come in and see that this is what this family needs and this is what – these are his needs. I make sure that I have medical histories and everything close, that again if somebody came in they'd be able to know that he's had, you know, he's spinal fusion and he's got metal plates and he's got PTSD and he has dementia. And you know, try and be as organized as you can be. You do. It's like running a small business."*

There was an uncomplicatedness when this caregiver questioned life and fairness, *"You know, you look at this person and you try and remember, why did I fall in love with you or you know the quality of your life stinks, you know why? Why did this have to happen to us? We didn't deserve it. You know, we've worked hard and you go through all those emotions, you know, and you just got to figure there's a reason somehow, and you just do the best you can because at the end of the day, you get into bed and you just say, I did what I needed to do to make his day good and mine as good as it could be, so tomorrow will come and all the days after that...."*

Caregiver spouses spoke in positive ways about the future, *“I know I’m getting myself prepared for the time... [when my husband is very impaired]. My destiny has been written; it’s a real life.... who I am.”* Another spoke of couplehood and their endurance, *“We’re close. Oh, for sure. We’ve been together 48 years. Yeah, so we’re pretty close. (Laughter) I think we’re just – half of a whole, each of us. We’re a couple....and will be.”* And one spouse refused to be defined by the caregiver role, *“You have to have that mindset that this is not... this doesn’t define who I am. It’s what we have to deal with right now and we’ll deal with it.”* She was presently oriented and was “being in the moment” for her husband’s care.

The caregiver co-researchers who described their relationship closeness, shared powerful thoughts and feelings. They illustrated a journey from start- a biographical story of couplehood, to finish- a realization of life with dementia, but the finale is still unknown, enigmatic, and indefinite on a timeline. ‘Keep on, keeping on’ was a mantra for spouse caregivers who recognized they had miles to go.

### **Empirical Variations**

When performing empirical phenomenological reflection, the goal is to reduce and distill the participant fundamental descriptions into essential constituents of the fundamental structure of the phenomenon. All sixteen participant caregivers’ narratives could be illustrated in terms of constituents, i.e.: the discovered themes, as described above. Their stories permitted a connection of the meaningful statements to the theme and subtheme. In the descriptions of the following themes, the author describes different viewpoints and elements in a general manner. But, as a research exercise, and to allow the readers further understanding of the descriptive manner of eidetic reduction, the following evidence permits a rich look into subthemes, in essence delving below the subthemes via empiric variations (See Appendix K).

All participants illustrated the subthemes of 2c. Knowing the Disease, 3b. Cherished Moments and 4d. Balancing the Scales. The themes were easily recognized and appreciated as they emerged from the dialogal interviews, however the nature in which the subtheme was executed or acknowledged differs. For example, in the Theme 2c. I See the Dementia: Knowing the Dementia, significant statements and formulated meaning were characterized with overall commonality and yet unique. Caregivers wanted to know more about the disease, or, they knew the disease had an unpredictable element, and some of the caregivers did not relish knowing the disease.

In the next example, theme 3b. I Feel the Dementia: Cherished Moments, caregivers described tenderness from and to the care-recipient in which there was a verbal, nonverbal or general impression of being loved or beloved. There were also cherished moments when the couple shared mutual activities, and still found life at present could be convivial and happy for a period of time. Finally, there were cherished moments when dementia did not seem as acute, and the care-recipient said or did things that were very much appreciated and reminiscent of the way things used to be.

In the third example, theme 4a. I Respond to the Dementia: Advocacy, surveillance, parenting the child, protecting or shielding, setting limits and controlling the situation were identified. In the final example, theme 4d. I Respond to the Dementia: Balancing the Scales, caregivers used humor, and sometimes expected humor from their care-recipient spouse. Other spouses relied on self-care as an important component of keeping the scale balanced and RC appreciated. Religiosity and spirituality were employed by caregivers to embrace their care-recipient spouse and find strength. Finally, for some couples, additional and some unconventional caregivers were added to the dementia story; it could be described as a tapestry



of care. Besides immediate family, church and neighborhood community, the Veterans Administration, and home health and private companions entered thy dyad to contribute to care. It contributed to and put a new halo on relationship closeness. Two caregivers identified their pets as integral to care; the pets extended the relationship closeness of the dyad and increased a three-way feeling of closeness.

### **Validation of the Findings.**

The author attempted to contact via telephone, the first five co-researchers who participated in this study. The aim was to share the status of the study, and to ask for their input and clarification concerning some nodes and resulting themes that were in draft form. Two spouses were reachable. The author shared a working version of the exhaustive description of the phenomenon with them. They offered extraordinary insight. One disagreed totally with the notion of *tabula rasa*- a clean slate. Other spouses reported a common occurrence of how, longitudinally, it was sometimes easier to care, because the care-recipient could not remember an unpleasant event from the day before. With this input, the researcher removed the node as an essential element, but it became an empiric variation for balancing the scale. The other participant was agreeable with the description. She was adamant that “dementia stories” of diagnosis and the visible symptoms, were singularly important as the reason for changing RC. She went on to describe the events as a historical account for spouse, children, and family. She said it was a red flag or a milestone that from then on, things were different causing RC to change. Thus the author moved it up in importance to a major theme. Of the other three participants, one spouse caregiver shared he had admitted his wife to long-term care for functional disability; he was too stressed to participate. The other two co-researchers were unavailable, both traveling out of town.

After receiving the guidance of the two spouses, the researcher continued to accept participants in the study always being mindful of saturation. With an additional nine co-researchers, it was imperative to read, re-read and dwelled with fourteen transcripts; the researcher reviewed and edited significant statements, readjusted subthemes but retained the main themes. It was a matter of looking at how inter-subjectivity expressed itself and how the author continually looked at the relationship between the caregiver's statements and how they connected to other caregivers' narratives.

Emails were sent out to elicit a second input for reviewing the exhaustive description. Six participants were reached, one of which explained his wife was admitted to a memory center and elected not to participate. By email, five participants were overwhelmingly positive and agreed that the description fit with their relationship closeness experience of dementia. One said, *"Very poignant. In some of it I saw our conversation. In some of it I saw the future. In all of it I saw your empathy."* Another participant wrote, *"This is thoughtfully & beautifully written. It made me cry. Would you mind if I shared it with my children?"* And another remarked, *"This is beautiful, just beautiful. Your ability to put together so many different yet similar experiences is lovely. Thank you for letting me be part of this."* Another participant stated, *"You did an excellent job of capturing what the feelings are of the spousal caregiving. It is indeed a journey. Certainly, not one we would choose, but nevertheless trying always to be together."* A Caregiver husband said, *"You have captured the way I feel perfectly.....in and out, up and down and changing, from word to word."*

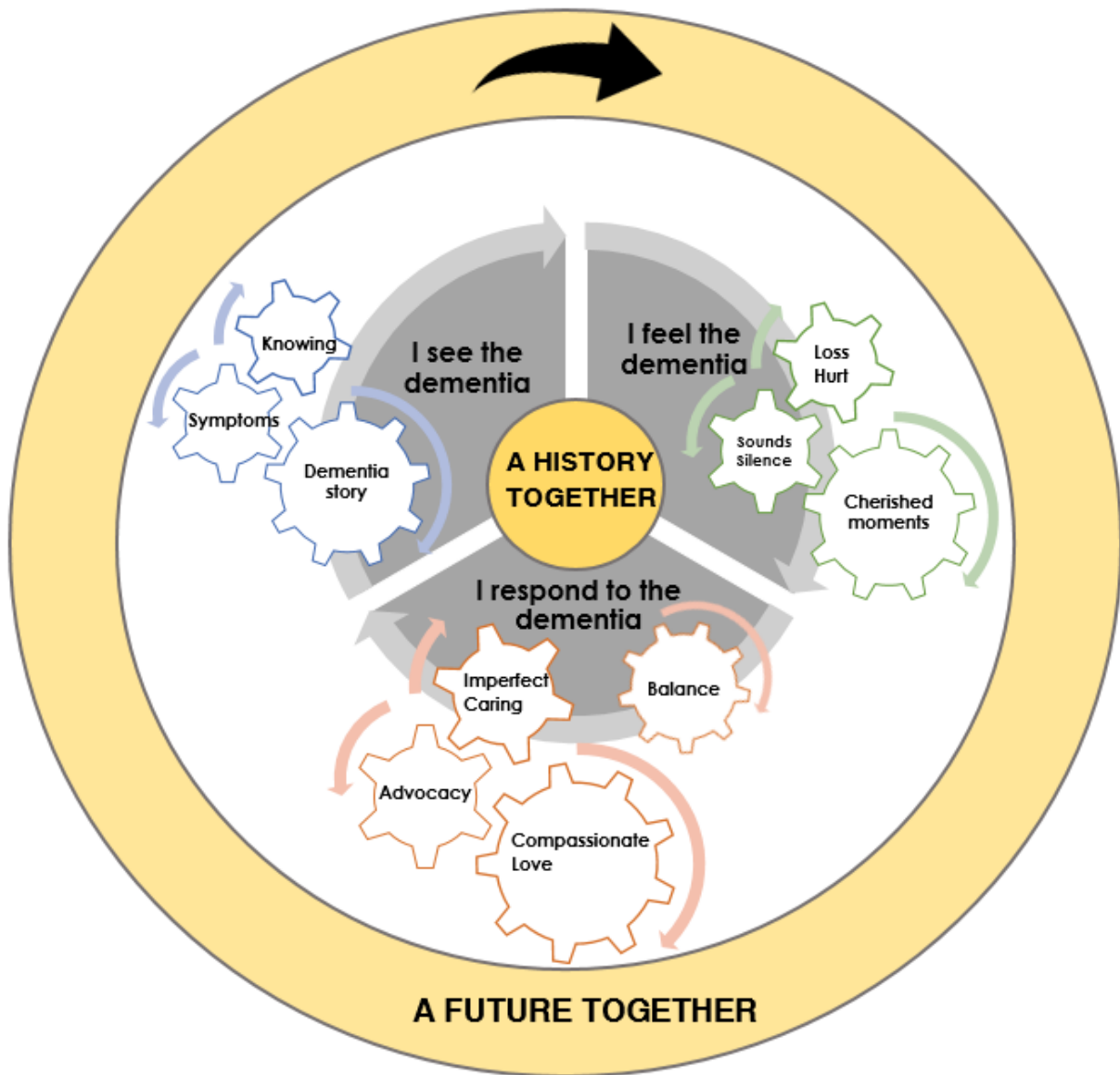
The researcher received more requests to be participants and capped the sample with another two co-researchers who seemed to want so to participate. After their recorded interview, they were asked if they would like to give feedback regarding the exhaustive description to date.

One responded in an affirming way. The final validating co-researcher, too, approved it; it seemed to him a very legitimate reflection of the journey from a caregiver's point of spouse caring in a dementia marriage. He shook his head, and remarked, "Yes."

## Summary

Spouse dementia caregiving subsumed many roles of spouse for both husbands or wives. Their challenge to be the spouse of a person with dementia was implausible. This chapter has provided the composition and the foundation of understanding relationship closeness in the face of dementia. The five identified themes constitute the essence of the phenomenon under scrutiny (See Figure 12.).

Every dementia spouse caregiver that was interviewed had an inherent strength, a genuine caring commitment, and kindness. They self-described as losing the bloom of love found in early marriage, but the physical living together and the historical knowing each other connections remained intact. Although the author saw them as a singular pillar of care, they were quick to say; they couldn't do it alone. This caregiver participant recognized dementia disease, apart from her sole commitment as wife to her husband, couldn't be done without help. She learned that on her dementia journey. And, she summarized it incredibly well, "*It takes a village for this disease. It takes more than one person, people and things, and money and time. It really does. I myself have said this same thing, I just think I knew what all this service was all about. But until you're living in it, you really don't know.*"



*Figure 12.* Visual presentation of constituent elements.

The next chapter will further expound the phenomenon and meaning of dementia spouse caregivers' relationship closeness as the findings: a comprehensive fundamental structure, and discuss limitations of phenomenological studies and implications for future research, nursing, clinical practice and health policy.

*And so, knowing that I have the expectation, that no matter how little of her mental capacity and her language skills, or whatever might be there...*

*I know she will always be there.*

*So, that's making it possible to sort of face what's coming,*

*and know that the closeness will still be there. Participant 006a*

## **Chapter Five: Discussion and Implications**

In this chapter, the author reflected on the data, the findings and the description of dementia caregivers' relationship closeness to their spouse. It encompassed due consideration of the disease and the symptomatology that is now part of the caring spouses' lived experience. The author had three goals, the first to discuss the phenomenon's fundamental structure and meaning, and how the findings relate to current RC research. A second goal was to critically evaluate the research project and pose future research directions. The last goal arrived at through the author's steps in this unique phenomenological study and empirical phenomenological reflection, identified implications for clinical practice, specifically: empathy and paradigm shifts.

### **Interpretation of the Findings**

The first goal was to report discoveries of the phenomenon as the fundamental structure and essential constituent meanings via Colaizzi's four operations. Operation One used the author's individual phenomenological reflection as described in Chapter Two. The IPR employed imaginative presence and memory to cross-examined the researcher's beliefs, values, and assumptions regarding her knowledge, experience, and thoughts about the phenomenon. The result was a preliminary discovery of a fundamental structure of the phenomenon. According to Colaizzi (1969), the IPR presumed the ability of a researcher to generate descriptive statements about any and all possible variations of the phenomenon as it appears to the investigator. It

seemed to contradict the bracketing of van Kaam and Giorgi's phenomenal study. However, Colaizzi was clear that the investigator must allow the participant to have free reign over the interview discourse; they own the experience. At this point, the IPR offers no associated meaning other than RC was an existential experience.

The author's discovered fundamental structure revealed married dyads had an ambiguous RC. Relationship closeness responded to CI-NPS and functional losses in a resonant pattern, much like standing and harmonic waves in Physics. A timeline of progressive, yet unpredictable symptomatology impacted RC via the senses. The results were: hurt, role loss, and different choices and changes in almost everything. It was a repetitious dance of connections, together and separate. The dementia was unique for each couple; and how the spouse caregiver reacted also defined their personhood.

Operation Two was fully described as the phenomenal study in Chapter Four, Table 7. Operation Three used organized data from the dialogal interviews and with reflective activity, determined meaning, or the 'so what' of the study. There were implicit and explicit meanings. Colaizzi borrowed from interpretive phenomenology and stressed meaning in his findings. Operation Two, Three and the meaning of the phenomenon are succinctly reported in Table 3 and Appendix J. The existential phenomenon of RC as described by dementia spouse caregivers and the author's IPR are combined to describe the fundamental structure and its meaning.

### **The Fundamental Structure**

Spouse caregivers spoke about their relationship closeness with dementia caregiving in a temporal manner, a journey, if you will. The biography of their couplehood was evident by funny and colorful, thoughtful and rich, happy and sad anecdotes they share. Spouses often told their story based on memories, photos and albums, mementos, the house and furniture where they

lived, their careers, and for some, the children who are their legacy. *Togetherness, closeness, love, admiration, romance, cooperation and sharing* were representative of the pre-dementia spouse and their dementia husband or wife. Dementia was an uninvited guest to their home.

The diagnostic medical appointment or the realization of actual symptomatology was a milestone in the dementia journey. It was the beginning, ...the starting point for a road less traveled. It was the evidence, the cause and the reality for formidable changes in the trajectory of the couples' life expectations. Sometimes the official diagnosis was put aside, but the awareness of the disease symptoms and behaviors became paramount and could be measured twenty-four hours a day... day and night, awake and sleeping. They produced the new look of the couple's love, responsiveness, communication, meta-connections, and intimacy. Spouse caregivers deliberated on whom their spouse was, compared to who they are now. This comparison only became relevant with the advent of a dementia diagnosis. Spouse craved the old, resisted the new and adjusted to the now via displays of affection, gaze, touch and "no" touch.

Caregivers saw the dementia disease for what it was. They used words like memory loss, forgetfulness, can't do anymore, or no-longer-smart, to describe the cognitive impairment. To define behaviors, they used terms like anger and agitation, can't sit still, goes-off, anxiety, and confusion. The caregivers talked about circadian rhythm disturbances that seemed to make their care-recipient spouse confused, out of touch for the day, and difficult to manage. The confusion could erupt unpredictably. It could manifest as delusions, uncooperativeness and resistance as well as, apathy, low energy, and extreme fatigue. They described their spouse as different people from whom they married but with the sparing of some innate personality characteristics. It was those features and traits that rescued, and sometimes temporarily restored an intimate connection. Spouses who desired to be active doing things, going places and meeting people were challenged

to be inclusive of their care-recipient spouse due to complex disabilities. They based relationship closeness on sharing people, places and things, both good and bad. The spouse caregiver's life was intertwined with dementia, and they were very absorbed with gaining knowledge of what it is, how to deal with it, and what it will become. They tried to fix the relationship between the two with understanding and empathy.

The dementia spouse caregivers felt the disease. Spouse described their loved-one in terms of loss and justly found dementia to be a hurtful thing. They described both provoked and unprovoked hurt from their mate and rationalized it as unintended, misunderstandings, and due to the disease. However, there were times spouse caregivers described the person with dementia purposefully hurting, physically harming and dismissing them. It was a paradox of knowing they would not have done that in the past, but now they do. It evoked questions of who is this new spouse with whom the caregiver was living.

They saw the losses most prominently as the diminishment of the care-recipient as an individual, whose autonomy and decisional capacity was disappearing. The personhood loss was conflicting because it was those very personable traits that initiated the vows, commitment, and marriage. They felt dementia's losses viscerally particularly since the existential loss encompassed the spoken and unspoken lexicon of love. Affection as they knew it, faded or altered. Many caregivers felt wounded as well as offended and angry by dementia's influence on their relationship with their husband or wife. There was a continual comparison of the past with the present. The person whom the care-recipient is *becoming*, was described as a shell, who generally looks the same, has the same voice, fragments of the same humor and intelligence, and has corporal habits that are familiar, but the essence of *who they are* changes.



Communication literally and figuratively was diminishing. Loss of language was a two-way street in dementia. The care-recipient speech was physiologically impeded, and the spouse caregiver found interpreting and responding, trying and exhausting. There was a loss in the meaningfulness of conversations, so the familiarity of the past becomes a safe- haven and reliable refuge. The connection with their loved one at the highest meta plain of consciousness was vanishing. Besides silence, there could be noise in the home too- loud, brash and illogical. Life could be unpredictable. Miraculously, there were magic moments when the dementia symptoms abate. The couple enjoyed minutes, hours or days of peace and harmony. These moments heralded the reappearance of a familiar sense of humor, a delight in a favorite food, a smile or astute comment. That cosmic karma made the caregiver sigh, laugh, question their preconceptions of the disease, and most of all renewed their energy and hope and reestablished a relationship closeness if it was lost.

Dementia spouse caregivers responded to the dementia disease. Relationship closeness and love was not lost but expands changes, ebbs, and flows, and exponentially increased in some ways to provide compassion and empathy. There was a need to maintain the care-recipient's dignity and mitigate stigma of dementia disease. There was a pervasive desire to protect from injury, as well as from people who are unknowing and unkind. Spouse caregivers provided all manners of care, by themselves and with help. Caregivers knew and recognized their limitations, and never ceased trying to be better at caregiving and better at accepting who their loved-one has become and is becoming. The spouse caregivers were pragmatic in planning; became adept at compromising and flexibility. Spouses readily found an inherent ability to give more, do more and at the same time, settle for what dementia disease has dealt them. That does not mean they did not question the fairness of the situation or their dreams of how it would be if dementia was

gone. There were thoughts of escapism. There were attempts to preserve the present with routine and ritual. The spouse caregiver used humor, spirituality, and a tapestry of care to facilitate their dementia journey. Spouse caregivers enlisted the help of family and friends, beloved pets, neighbors and community services to strengthen commitments to their dementia spouse. There was a desire, yet a hesitancy, to know more about dementia. Nevertheless, the couplehood endured with a new sense of identity, purpose, and commitment.

There was a perceived future for the couple. It was related as having been bound by vows and commitments and as a deep abiding love, an oath, pledge or a promise. The future could just as easily be a friendly compassion delivered with intentionality. Dementia spouse caregivers described how they were bound and determined to provide the best care possible in their situation. They spoke of a future for the dyad in thought- reminiscences, and deed- a practical course for the eventual delivery of custodial care. Above all, caregivers spoke positively of their relationship closeness and continuity as a couple despite, and in spite of, dementia.

### **The Meaning of the Phenomenon – the Gestalt**

Heidegger (Stassen, 2003)) and Merleau-Ponty (1962) suggested meaning making processes go beyond verbal communication exchanges; that they are based on interactions and sensory perceptions beyond cognition, and are found in an embodied communication and intentionality. Similarly, the dementia dyad demands a constructed meaning of experiences, not just within a deficit model, but within a dyad willing to explore adaptability, negotiation, and acceptance (McGovern, 2011). The spouse caregivers in this phenomenological study were process oriented, i.e.: on a journey, challenged by altered relationship closeness. There was not an absolute loss of RC, so much as a variability with emerging expressions different from physical and sexual attractiveness, eruditeness, beguile and charisma. The RC tended more

towards a compassionate, benevolent and respectful relationship bond. Caregiving in the context of dementia spouses introduced unique assumptions about finding meaning (Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken, 1991). Farran et al. (1991) suggested that existentialism, specifically finding meaning through suffering, was an alternative theory to understand dementia family caregivers better. Alternatively, the salient work of Frankl (1963) in “Man’s Search for Meaning” suggested an important caregiving postulate, that of the existential choice to give care, which is significantly influenced by societal conditions. To freely choose to give care, the caregiver must explore the imaginative variation of not being a caregiver; a narrative illustrated in this phenomenal study. Spouses thought and dreamt about walking away and turning the key, walking through the door and leaving. However, when confronting the choice of caregiving, the spouse caregivers must also explore free choice vs. existential guilt. This mimics the spouse’s theme of imperfect caregiving and future RC in light of possible custodial care and long-term care, and all of the culpability that brings. See Table 8. for expanded meanings related to the fundamental structure.

Table 8.

**Constituent Characteristics of the Phenomenon and Meaning**

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Theme 1. A history together meant that life together was mutually desirable, acceptable and when reminisced, it was comfortable and tolerable, if not satisfying.

Theme 2. I see the dementia

- a. We have a dementia story highlights a perceived catastrophe, that dementia meant from now on, things between the dyad are different.
- b. Naming the symptoms meant that the caregiver recognized CI-NPS as challenges and roadblocks to their desired relationship closeness.
- c. Knowing the disease meant that the caregiver spouse could apply an existential meaning that the person with dementia was different due to the disease, not an intentional severance of the relationship closeness between them.

Theme 3. I feel the dementia

- a. Loss and hurt allowed spouse caregivers to existentially feel the visceral and psychological hurt of CI-NPS.
- b. Sounds and silence permitted an existential auditory sense of experiencing relationship closeness loss.
- c. Cherished moments meant an existential hope, meaningful activity and recoupment of the lost RC feelings.

Theme 4. I respond to the dementia

- a. Advocacy was a distinct replacement for RC as a tactile, visual and auditory, cognitive, and intentional activity to assert the existential concept of relationship closeness.
- b. A compassionate love arose as something different from socially accepted concepts of love; the qualities of tenderness, nurturing, and benevolence becomes intrinsic to the relationship.
- c. Imperfect caregiving questioned the RC actions from spouse to care-recipient and emerged naturally waxing and waning, as human nature prevents achieving the existential concept of perfection.
- d. Balancing the scales recognized some sort of choice is involved with caregiving and intentionality of RC in different domains.

Theme 5. A future together described an intentional continued personal involvement in the future, maybe in a new relationship closeness context.

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In exploring the meaning of spouse dementia caregiver's relationship closeness, the readers are asked to appreciate the contextual experience of 21<sup>st</sup>-century view and stigmatization of the disease via mainstream media; media are a formidable society tool with persuasive abilities. Van Gorp and Vercruysse (2012) performed a new inductive framing analysis of the phenomenon, a concept from social psychology, to identify dementia meaning in a media content (books, AV material, and health brochures). Their findings reported a firm dementia stigmatism that 1) the mind and body disassociate; 2) dementia is portrayed as a thief, assassin, and intruder; 3) medical science must be armed to fight dementia; 4) there is a fear of dying and death awaits;

and lastly, 5) prevention of dementia is unrealistic. The investigators countered those negative themes with reversed roles as well, suggesting that dementia allows

1) reminiscence of seeing childhood again; 2) a good mother role is assumed by a caregiver; and 3) carpe diem- there are still cherished moments to enjoy. Sadly, themes with 1) a callous view of persons with dementia with unhappy outcomes, 2) other's immorality and unkindness in general, and 3) particularly obvious harsh metaphors are still in play contextually in the books we read and films we see. Few articles, stories, and movies assume the viewpoint or the experiential context of dementia. Likewise, a 2016 study by Stites et al., reported older respondents' expectations were that people with dementia would naturally receive less support, have limited social interactions outside the family, and likely face institutional discrimination. Females, compared to males, in their study reported more pity but weaker reactions to dementia's adverse aesthetic features. This study suggested woman may be more tolerant of functional loss and CI-NPS. Moreover, those in the study who thought dementia was a mental illness, rated CI-NPS more severely than those who knew dementia was the cause. This study surmised that these social beliefs could be extrapolated and applied to caregivers, family, and friends of persons with dementia in our communities resulting in a diverse range of RC when posed with dementia.

A successful study should contribute meaning, and new ideas and perspectives from findings and serendipitous discoveries. Colaizzi found in his study (1978a) the joint efforts of the methods IPR and EPR allowed him to identify distinctions in learning. In the author's study, it allowed the surfacing of relevant constructs and conceptual thoughts related to the relationship closeness linked to the dementia spouse caregiving paradigm. In the present study, the author did not cite the term "caregiver" in her IPR. Moreover, in the transcribed narratives, only two of the

sixteen participants spoke of being a caregiver or caretaker per se, and in a very limited way. They were both medically oriented professionals. In addition, one participant talked about being in “*this*” - meaning caregiving role but didn’t term it as such. The author provided that context in transcription. Another interviewee spoke of being part of a caregiver support group. Participants saw themselves first as spouses, then partners challenged by dementia disease. So perhaps, it is the author and other researchers who label the role as a *caregiver* inaccurately. Moreover, “caregiver” is the term often and freely discussed in the dementia medical community. Perhaps we are wrong using this keyword.

The term caregiver raises interesting opinions about the scientific community’s presuppositions of using the term caregiver when perhaps it should be “carer,” as in United Kingdom’s parlance. Colaizzi (2004), in his last and unpublished discourse eloquently though melancholically philosophized a re-interpretation of phenomenology. He used the term Care, with an intentional capitalization, to describe authentic life-world experience intertwined with the love of philosophy and phenomenology. He stated,

No things can be significant that are not issues for our involvements, concerns, dealings, and intercoursings. Whatever we are not concerned about intercoursing with cannot be the significant things themselves. The significant things themselves can never be abstract or even "neutral". The things themselves, then, are significant unreversed originals with which we intercourse, that is, the things that we have Care for appropriately intercoursing with. The things themselves thus can be nothing other than significant, unreversed, original, genuine world-beings with which we properly and caringly intercourse...

Care bestows all significance (as cited, p.2).

He goes on to describe willful exploitation without Care, suggesting that “things” in the world without Care can be manipulated, profited by, objectified and disposed of; they become vulnerable. However, through phenomenology and human intercoursing, world beings are no longer “*thingified*” or solidly fixed and “*unfluid*.” “...everything is fluid and world-beings are never fixed but are always changing in their give and in their resistance, in their appearance and significance, like mountains at sunset, themselves stretching along and varying with Dasein's stretching” (as cited Colaizzi, 2004, p.5). His phenomenological philosophy of a researcher's Care in striving to understand life-world is an apt metaphor for this study's phenomenon in that Care, too, sheds a beam of light on dementia dyads and their changeableness in relationship closeness both from the study's point of view and the spouse carer's Care.

This author-researcher proposes relationship closeness then is a construct in which caring assumes the components of nurturance and some form of love or benevolence as is well documented and accepted in society. Additionally, the capability to aid, coach and advocate, not necessarily “give care,” are also components of RC. Moreover, perhaps “caregiver” is too contextual with professional and para-professional medically oriented caregiving. So, the question is, do dementia spouses see themselves as caregivers, and might that be a stage-specific role equated with functional loss? Moreover, would a caregiving role equated with burden alter their RC?

Secondly, spousal self-care was identified in context with relationship closeness. It was part of the foundational strategy to be a good spouse in dealing with dementia. Specifically, the theme of balancing the scale identified how, if a spouse did not personally control the situation, did not get respite, or have help, they could no longer give to the couplehood the energy, the emotions of respect and dignity, and freely choose to tolerate CI-NPS. This was especially

evident in the themes imperfect caregiving and future together. If the unaffected spouse could not remain well or was incapable of dealing with the care-recipients declining health, functional losses and NPS exacerbations, then the marriage would dramatically change. It would no longer mimic the conventional exemplar of an “old married couple” or the typical dyad aging together in the community, to one of anticipatory grief for a husband or wife “in care” – long-term care.

The phenomenon studied was relationship closeness from the view and experience of carers who live with dementia spouses. It engaged descriptive and interpretive phenomenology, factual essences (Merleau-Ponty, 1962) and deep reflection by the author. It does not offer generalizability to a cohort of spouse carers, nor does it measure RC in an empirical, quantifiable way. It does, however, offer the author’s individual phenomenological reflection and epoché, rich descriptive protocols, exhaustive description, parsimonious constituent elements and discovery of a fundamental structure, and a meaning, zeitgeist, or gestalt of the experience. Dementia dyads maintain an RC that is altered temporally by fits and starts and vacillation, by CI-NPS.

The study questions were, what is the fundamental structure of the phenomenon, and what is the meaning of the phenomenon. It is not to explain or find causal relationships. The study findings suggest that the phenomenon is temporal, complicated, embedded in a notion of contextual dementia symptom experiences, and results in the requirement of a spouse carers to make sense and meaning of what is happening, thus reconfigure their preconceived notions of marriage, relationship, and couplehood. There is much more to dementia caring than variables posed by medicalized dementia care research usually illustrated as dementia stage, burden, and coping. To examine dementia spouse carers’ relationship closeness, the researcher used a single



open-ended question allowing a wide-ranging response from spouses, but always coming back to relationship closeness in light of dementia disease.

### **Study Limitations**

In true phenomenology, the findings stand for themselves, and as this study's dialog protocols were the unique narratives of the co-researcher-participants, they cannot be critiqued in the rationale of empiric scientific criticism of what is true, reproducible or a functional causal relationship. Therefore, there are no limitations found in the discovered essence of their experience; criticism is a moot point. The author believed the study itself, and discussion above stand as a significant contribution for its originality, as well as its attempted precision in following methodology of organized data that were rigorously analyzed. In that manner, it was a quasi-empiric replication study. The author took some liberties, as per Colaizzi, with mixing descriptive and interpretive phenomenology. Like Colaizzi, this was also a hybrid study. It focused on a predetermined phenomenon that was slightly an atypical approach. It had a goal of adding a scientifically, almost medicalized basis, i.e.: dementia symptoms and neuropsychiatric behaviors, which would frame the participant's description of their relationship closeness. This is not the usual approach in unstructured, free-flowing phenomenological investigations.

The author did not include follow-up questions, or a more thorough questionnaire format for participants based and built on ongoing data analysis as Colaizzi fashioned in his written surveys. It did not specifically ask the co-researchers *meaning-making* questions at the end of the free flow dialog or in written manner like Colaizzi did. However, meaning still prevailed.

The methodology implemented for this phenomenological study was an attempt to replicate a phenomenological method employed in Colaizzi's dissertation and subsequent publication concerning the evolution of learning (1969, 1978 a). Colaizzi postulated that an

Individual Phenomenological Reflection, i.e.: *Colaizzi's IPR* of learning via reading a new book, could adequately describe the fundamental structure of the phenomenon of learning. He tested that premise by also executing a typical van Kaam phenomenal study using a plurality of subjects. His goals were multiple. He selected learning as a conduit for the execution of a phenomenological study because it was naïve territory- its fundamental structure and fundamental description had not been previously published. Colaizzi stated despite the vast quantity of empirical and theoretical research unique to learning, it surprisingly remained an uncertain and ambiguous phenomenon and in that way, was a perfect vehicle to examine and test. He succeeded in applying and describing the abstract and ambiguous procedure of phenomenological reflection. He identified the essential elements of learning that were previously only concentrated on performance and behavioral laboratory testing. The experiential descriptions found the learners' experience included progression of situation – to task – to material via a continuous learning of parts, completion and personal achievement.

To allow a more profound meaning for this dementia study, follow-up questions via an instrument and an actively engaged dialog between researcher and spouse participant/co-researcher would provide more meaning and sense of the experience. Colaizzi (1967, 1969) used specific survey questions to hone-in on the existential meaning for the sample of learners. It was revealed by the items on the last page of his questionnaire upon completion of the learning task. In his thesis, questions were asked, such as did the participant identify change pre-and post-task, and if so, how did it come about, what caused the change, what explains the change, and why did the change exist for that respondent. A follow-up to the present author's study could be those types of queries related to RC, the experience of being a dementia carer, and recording the

participants' personal meaning, i.e.: meaning-making of changes to their own RC in more accurate terms.

The second criticism of this study is related to demographics, traditionally beyond the scope of qualitative research, that identifies study limits and are more common to empirical and scientific studies. From an empiric view, the recognized scientific limitation of this study was the narrow participant sample demographics due to a biased, purposeful and convenience sampling. Phenomenology must be practiced where the experience is situated and is contextual, and this study achieved the lowest bar of inclusion criteria and praxis of executing phenomenological research using Colaizzi's pedagogy.

The participants were white, middle class, well educated, and proactive in seeking supportive care, including the opportunity to participate in this study. They were especially eloquent in their narratives. This thumbnail slice of dementia spouse carers does not reflect the diversity in Southeast Connecticut. It does not include racial and cultural differences, or mirror LGBT married partners, or address non-married co-residing partners who, in theory, assume spousal roles (just not in the legal or economic domains). It did not identify interpersonal violence as is documented in the literature.

This study does not reflect dementia as a disease or its epidemiology in the United States, with young onset and a myriad of typologies with and without co-morbidities; it does not reflect the variances between mild-stage disease with slight functional losses and the severe stage disease with major functional impairment requiring considerable custodial care.

For more than one-half of the participants, this was their first marriage, and the longevity of their marriage exceeded 50 years. Conversely, it does not identify any disparity of ages between the dyad members, the late life married, the second and third marriages and the

marriages of companionship and convenience versus romantic love. This study does not explore sexuality. Also, separating the male and female genders may modify the fundamental structure.

The sample did not identify couples who had poor versus good pre-dementia relationship closeness, nor did it address premorbid marital discord, abuse or intimate partner violence, prior separation, or any suggestions of the possibility of divorce. The author saw this cohort as a well-married, proactive, participatory sample who voluntarily engaged in a discourse, allowing a researcher to record their stories; it was their unique description of their life that was parsed with reflection and empathy. However counterintuitive, the intersubjectivity findings rang true for those interviewed. Saturation of this sample occurred despite the narrow social and economic demographics. This study captured only the experience of that exclusive cohort of participants.

### **Recommendations for Future Research**

Growing evidence shows there is a link between carers and care-recipients' prior and present relationship closeness (amount of interaction, intimacy, communication, caring and coping), symptoms of dementia (CI-NPS) and caring outcomes in a bi-directional manner. When interventions were reviewed, some authors suggested optimizing the dyad relationship could improve caring outcomes. However, that can only happen with attention to future research that expands what is known about relationship closeness, quality, and intimacy (Edwards et al., 2016).

The initial problem is the RC terminology and measures for potential use in a primary care clinical practice setting. They must identify risk factors of poor RC in addition to typology and effects of CI-NPS (i.e.: translatable research). Currently, the instruments are not feasible (i.e.: time required or extra staff: social service, neuro/psychologists) and are not clinically meaningful. New measures are a mandate. Researchers know risks exist for morbidity and

mortality, hospitalization and institutionalization, relate to the person with dementia's loss of cogent cognitive abilities and emergence of NPS. However, there are inadequate researchers and studies, lack of education to professionals and families, poor mainstream media coverage of dementia disease, and at the risk of offending academic and tertiary care institutions, there is difficulty accessing grants to small but participant-rich dementia practices that can afford meaningful results.

Recommendations can be categorized within three frameworks: relationship closeness, cognitive impairment, and neuropsychiatric symptoms. Using demographics as tactics to narrow cohorts to subtypes based on type and severity of dementia, functional loss, and CI-NPS, as well as the spared domains that support RC, would advance dementia research. Other demographics of age, gender, ethnicity, education, socioeconomics, and geography would broaden applications of RC and CI-NPS interventions. The findings then could be applied to spouse and family carers as appropriate always mindful of carer and care-recipient co-morbidities.

In relation to the current state of RC research findings, spouses provided intensive and long hours of home care for dementia care-recipients. Their 'good' close relationship quality positively impacted caring outcomes to slow disease progress, sustain carer and care-recipient health, gain carer transcendence, as well as, limited institutionalization, and decreased expected monetary costs of dementia care. The gap in research, however, lies in the rigorous investigation of RC as a concept and fluid process that lies on a continuum of good to bad. There is limited knowledge how to successfully intervene in clinical strategies; it has so far been untapped in experimental research. Therefore, it is imperative first to conceptually analyze and understand RC and its ability to be measured. Next, it is important to provide interventions that maximize

the positive potential of interpersonal dynamics. And finally, there is a need to find ways to decrease the adverse risk of past or current, and non-therapeutic RC found in caregiving dyads.

More investigation of cognitive impairment is essential to understand the crossover in communication loss, non-verbal communication and a dyad's new language of dementia. As a critical element to RC, the how, where and why of speaking, communicating, plasticity and shared dementia languages, and dyadic understanding of verbal and non-verbal interactions must commence.

Finally, the expression of NPS and its taxonomy challenges, need careful nosologic research to inform clinicians and interventional researchers ways to capture meaningful data in a rigorous and methodical way. Symptoms of apathy and lack of empathy are mysterious and overlapping between NPS and RC, and the research to date has shown it is an important concept. At present, neuropsychiatric symptomatology is a complicated language of dementia behaviors, behaviors and psychological symptoms of behavior, and mental health adaptation of neuropsychiatric inventory of symptoms. Is there a short, more cohesive way to conceptualize NPS in a manner that allows a match for a ranked estimation of how intrusive and disturbing the NPS is, or becomes, within the dyad?

The perspective of the author's view of the future of phenomenology is that it is a work in progress. New technology affords interesting methodological opportunities. The internet, blogs, Skype-type applications, survey monkeys, and social media's Twitter, Facebook, and website comments allow an unfettered look at the mainstream population's thoughts, beliefs, and emotional responsiveness. It brings with it a new sense of ethical considerations as well as challenges to reliability. Husserl and Heidegger likely didn't have the opportunity to integrate the medium of film into their philosophy and research. Colaizzi's premature death at the age of 62

prevented the advancement of his reflective methodology that may have been augmented with current scoping abilities online. However, perhaps phenomenology cannot accommodate technology when existential experiences are being investigated. Giorgi (2014) spoke about phenomenology as the basis of human science psychology. He reported that the APA [American Psychological Association's] were serious to permit psychology in as a STEM (science, technology, engineering, mathematics) science. Supporters of STEM emphasize natural science, technology, engineering, and mathematics will homegrow U.S. students to regain a technological edge in entrepreneurship, research and development. Giorgi responded there was a dichotomy in the importance of expressionism and physiognomy swimming against the scientific tide of the times (as cited p. 234). His remarks suggested he held only with the “onlooking” researcher approach. Nevertheless, this author’s question is, can vocal biomarker and emotion interpretation software (BeyondVerbal.com, 2017) offer an adjunct to Lifeworlds impression-expression structure. Is it possible to include more technology, or is phenomenology still purely the “Logos of the Soul” (Churchill, 2012)?

No matter the methodology, empiric or phenomenological, rigorous dementia family research should be directed in a scaffolding manner to provide foundational studies leading to treatment protocols. It is of paramount importance that diagnosis and treatment of a person with dementia must be delivered as a family, caregiver or community model. The person with dementia has the diagnosis, but more so, it is a family disease. Stakeholders, like spouses, family, kin and paid caregivers are essential in the design of dementia research programs. They must participate in determining the significance and hierarchy of research study interests, the direction, and formulation of ethical research, and the ways to promote invitations to participate,

when many clients are vulnerable, often housebound, and living in geographically-restricted communities.

### **Implications for Nursing and Clinical Practice**

Where care is concerned, adopting healthcare-friendly delivery models that promote personhood, recognize individual differences and instill ethical and moral acceptance is imperative. The first concept implicated by the findings of this study is the need for empathy; the second is a necessity of a shift in the current medicalized dementia paradigm.

An understanding of the experience of spouse carers' relationship closeness findings would not be successful if empathy did not ascend as a critical concept in dementia care. It is interesting that empathy is a philosophical methodology in existential psychology and even taught as a model and framework during psychiatric residencies, yet is not a fundamental component in other health care disciplines. However, Florence Nightingale (1859) asked her readers to imaginatively take the place of an invalid, essentially be dependent, in order to contemplate the effects of nursing behaviors. She commanded prospective nurses, to express the quality we call empathy. Norman (1996), in her investigation, identified two fields of empathy, one, as a modern English language concept to identify with another person or that person's actions; thus, putting oneself in another's shoes and positing some level of understanding. The other is a therapeutic cognitive skill for helping others, and it is teachable.

Edith Stein, a student of and first research assistant to Husserl, was a continental philosopher. She was an unfortunate casualty of the era, her gender, anti-Semitism and the competitive nature of academia. Her 1916 doctoral thesis on the problem with empathy posed the question, "I know that there are persons other than myself, and I know that these persons have



various psychological states and experiences. How do I know these things?” (as cited in McDaniel, 2014). McDaniel goes on to state:

Stein’s answer is that we know these things by empathy. Empathy is an irreducible intentional state in which both other persons and the mental states of other persons are given to us. In an empathetic experience, we are presented with not mere bodies in motion, but rather with persons – and they are presented to us as persons who are angry, or who are grieving, or who are filled with joy. Persons and their mental states are not theoretical posits or unobservable entities – they are objects of which we have something akin to perceptions (as cited on p. 3).

McDaniel gave the analogy of not seeing just faces but seeing angry, transfixed with wonder, and grieving faces. This echoed Merleau-Ponty’s elaboration that the insight of Gestalt psychologists of expressiveness, or physiognomy, was a perceptual datum (Giorgi, 2014). Like Stein, McDaniel made the case that empathy is unique, and in a class by itself. It is an experiential phenomenon given intentionally or revealed to us passively. It is similar to but not equal to a primordial experience in that there is a fullness or intensity of sensation, but in some ways fleeting and incomplete. At a minimum empathy is a prerequisite to know oneself is a person among persons (McDaniel, 2014).

The empathy of psychotherapy relates to a clinical process, the use of open-ended sentences, and expressing a clinicians’ wonderment at how the patient feels, thus allowing a dialog to ensue. McCarron, (2008) suggested the use of this technique when clients present with somatic complaints in which there seem no answers from medicine, no treatment, and no cure:

Empathy or briefly “becoming the patient” is a key component to developing a strong therapeutic relationship with the patient. The use of empathy can also

minimize physicians' negative feelings or countertransference. Truly empathic remarks such as "Having so much pain and discomfort must be difficult for you," or "The discomfort you have would probably be a challenge for anyone" are often helpful (as cited in McCarron, 2008, p.450).

There are four components of empathy: moral, emotive, cognitive and behavioral domains. Nurses and nurse practitioners, given training, could operationalize those processes by being non-judgmental and sensing the emotional distress in others; using heightened empathetic listening, they could critically analyze a client's perspective, and their verbal and non-verbal communication (Norman, 1996).

The development of a dynamic learning experience for carers of people with dementia that used virtual reality hopes to engender empathy and understanding (BBC News, 2016b; Veerbeek Willemse, Prins, & Pot al., 2016). Veerbeek et al. (2016) is a Dutch pilot study, with hopes to increase professional and family caregiver's empathy; it uses Virtual Reality apps for simulation, e-learning, blogs, and classroom methodology to introduce person-centered care. Similarly, Wiseman (1996), in her concept analysis, concurs empathy is a teachable and critical skill. A dementia clinical practice must employ empathy from clinician to both patient and carers to be successful.

The second concept implicated by the findings of this study is the need for an alternative dementia clinical paradigm. Thomas Kuhn (1922-1996) influenced Colaizzi's work and scholarship. Kuhn's incommensurability theories employed a modernist's view of paradigms. He claimed that the meanings of terms are interrelated in such a way, that changing the meaning of one term results in changes in the meanings of related terms. Thus, in modern technology and with scientific learning, advances in space, time, and matter force our conceptions of what one is,

and how things are viewed, to re-equilibrate in a matching process. That search for re-equilibration is searching in a meaningful way for the truth (Bird, 2013). Paradigms, then, are puzzles for researchers to solve. The author suggests as more is known about the psychosocial domains and dynamics of family dementia care, especially from the care-recipient's point of view, adjustment in the standard medicalized care of dementia will also change.

Dementia is modestly moving to more of a bio-psycho-social perspective today than in Auguste Deter's Germany. It is commensurate with the increase in advocacy groups and organizations. However, the world's overall clinical dementia paradigm remains very medicalized as a deficit-focused disease. A paradigm shift would support a more open, accessible, less stigmatized and health-wellness focused approach by clinicians. Dementia scales, measures and instruments; dementia staging language, and co-occurring NPS are all described in a negative framework as loss, deficit, impairment, bad symptom and belligerent behavior. A counter frame, uniting body and mind was offered by Van Forp and Vercruysse (2012). Their study illustrated renounced dualism that afforded persons with dementia to still retain a physical domain that was emotionally attached and related to life; the focus then could be placed, not on what is lost, but what remained. Emaux (1999) wrote in a simplistic, yet elegant way, "Existing is being caressed and touched" (as cited on p. 88).

Walmsley and McCormack's (2015) interpretive phenomenological study focused on eight senior care professionals. Based on findings the authors suggested care providers saw their role as delivering advocacy, integral care, and relational intimacy via a model that allowed family carers to connect what was with what could be. This echoes the present study as a comprehensive health model based on empathy, personhood and this study's themes of a journey rich in past stories and regular evaluation of who the dementia care-recipient and dyad were,

compared to present and future. Reminiscence is an important part of the dementia dyad experience.

Researchers and academic writers are slowly engaging in a more socially constructed dementia disease attitude. Stephen Post (2000) analyzed the objectification and medicalization of Alzheimer's disease and explained that we live in a hyper-cognitive society. He suggested our worth and personhood depends on self-control, independence, economic self-security and productivity, all at the expense of emotional, relational, aesthetic and spiritual qualities (Mayo, 2013). Post, an ethicist, commented on modernity's prevailing views and our contemporary existence in context with dementia, "Very simplistically, 'I think; therefore, I am,' implies that if I do not think, I am not" (as cited in Post, 2000, p.247). He posits the need to move beyond hyper-cognitive values and rather seek hope for persons with dementia, whom he calls the "deeply forgetful." Post considered faith, the enduring self, love and medical progress as the sources of hope for carers and *the deeply forgetful*.

A dementia paradigm shift must be considered as a framework for a 21<sup>st</sup> century's informed, progressive research and clinical care agenda.

## **Conclusions**

Overall, this dissertation contributed to the fields of nursing, medical anthropology, and psychology. It highlighted the health, neuropsychiatric and social dimensions of dementia diseases and how these components shape the experience of providing care to, and within, dementia dyads. In some small way, it unpacked the massive construct of relationship closeness for dementia spouses. It is possible to duplicate an academic qualitative study; however, it is impossible to imitate the philosophical thinking and understanding like that of Husserl, Heidegger, Sartre and Merleau-Ponty. These great thinkers spent their lives articulating

philosophy and existential psychology and were actively immersed in clinical, academic and professional practice based on philosophy. This study merely scratched the surface of the existential concept of RC and caring for a dementia spouse.

A phenomenological research method and methodology for studying relationship closeness of dementia spouse dyads have an advantage over traditional empiric techniques using instruments and statistical data analysis. For example, RC studies identify the links between some CI-NPS and caregiving outcomes, but they fail to report the complexity of couplehood's losses and forfeiture of dyad intimacy, roles, interdependence, and resilience. It is hard for quantitative research to capture the exceptionalism of dyads and their co-construction of a new life with dementia. This Colaizzi study enabled the researcher to illustrate the dimensions of relationship closeness from a dementia spouse's point of view, discover the fundamental structure and portrayed the spouses' lived experience in context with dementia disease. It succeeded in documenting a glimpse of a life that confronts a shifting, progressively terminal disease, and its resulting changeable, ambiguous marital life. It emphasized understanding the spouse experience and not determining causality. Erwin Straus, a phenomenological psychiatrist, offered a unique distinction in the findings generated by phenomenological investigations:

Such (understanding) investigations have, therefore, probably much less practical application than natural scientific research. But perhaps they may claim another kind of usefulness. The knowledge they see is not meant for mastering the world, but rather, for unlocking it and making world that is mute into one which speaks to us in a thousand places. The fullness and depth of our world is to be heard wherever, til now, it has been silent (cited in Strauss, 1963, p. 395).

This study is in keeping with Merleau-Ponty's (1962) essentially descriptive approach of the touch experience. It focused largely on the sensorial component of the spousal RC and aimed at less explanation and more understanding, even to the detriment of any practical value such as pragmatism, mastering or even conquering the phenomenon (Colaizzi, 1971). There is already a body of work that views relationship closeness mostly as a co-occurring process to other dementia caregiving research. Based on this phenomenological study, it can be concluded that the potential for future RC investigation is immense, and a panoply of research is needed to address current gaps and limitations. The design of global theoretical dementia models, new therapeutic interventions, individualized behavior modification, dementia care access, personalized medical algorithms, and cost control mechanisms are needed. We are quickly approaching the "Baby Boomer Tsunami," and the "Graying of America," when senior numbers are predicted to be doubled by 2025 and dementia disease will soar (Alzheimer's Association, 2017). Therefore, it is essential to destigmatize dementia, address the vulnerable subject requirements for dementia research, and vigorously enroll carers and care-recipient participants in prospective research. The pathway to change is via informed legislative groups, proactive Medicare innovations, and plans for the financial avalanche of need in the future. Empowering, engaging and educating spouse carers is a crucial first step.

*Although there is no immediate cure for dementia, there is hope.*

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## Appendix A

**Relationship Closeness Instruments and Elements**

| Relationship Closeness (RC) Instruments  | RC elements  |
|--|--|
| Burns Relationship Satisfaction Scale (Burns, 1983)  | Communication, conflict resolution, affection-caring, intimacy-closeness, and satisfaction   |
| CG Attachment Scale (Hazan & Shaver, 1990)   | Secure, avoidant, and anxious-ambivalent   |
| CG Avoidance and Anxiety Scale - Slightly Modified Version (Collins & Read, 1990)  | Avoidance (discomfort with closeness and dependency) and anxiety (fear of abandonment)   |
| Elder-Caregiver-Family Relationship Subscale of The Total Caregiving Burden Scale (Poulshock & Deimling, 1984)   | Anger, resentment, strain, manipulation, depression, neediness, negative family effects, dependence, relations with others, pleasure (negative code), and multiple demands |
| Family Adaptability and Cohesion Scale—Couples Version (Olson, Portner, & Lavee, 1985)   | Cohesion, change and communication   |
| Family Satisfaction Scale (Olson, Tiesel, & Gorall, 1996)  | Family pride and accord  |
| Four Items of The University Of Southern California Longitudinal Study Of Three Generation Families' Measures Of Positive Affect (Mangen et al., 1988; Lawrence et al., 1998)                          | General closeness, communication, similarity of views about life, and degree of getting along  |
| Intimacy Questionnaire (Morris et al., 1988) - based on research by Waring & Patton (1984) and Waring, Tillman, Frelick, Russell, & Weisz (1980)   | Affection, cohesion, expressiveness, compatibility, conflict resolution, resolution, sexuality, autonomy and identity  |
| Intimate Bond Measure (Wilhelm & Parker, 1988)   | Care vs. control; communication, kindness, understanding, domination, fun, affectionate, and critical nature   |
| Mutual Communal Behaviors Scale (Williamson & Schulz, 1995)  | Joy, reciprocity, specialness, reliability, responsiveness, problem solving, & devotion  |
| Quality of Prior Relationship Scale (Williamson & Schulz, 1990) based on: Subscales of The Dyadic Relationship Component of The Family Assessment Measure (Skinner, Steinhauer, & Santa-Barbara, 1983) | Communication, affective expression, and involvement   |
| Relationship Closeness Scale (Noelker, 1996; Whitlach, Schur, Noelker, Ejaz, & Looman., 2001)  | Mutuality, general closeness, demands, specialness, criticism, and communication   |
| Scale for the Quality of The Actual Relationship - Dutch version (Spruytte et al., 2000)   | Warmth, conflict, and criticism  |
| Social Interaction Scale (SIS) (Gilleard, Belford, Gilleard, Whittick, & Gledhill, 1984)   | Humor, anger, possessiveness, interference, strain, and communication  |

## Appendix B

**Global Deterioration Scale**

| STAGE       |  | DESCRIPTION  |
|-------------|--|--|
| No Dementia | Stage 1<br>No Cognitive Decline                | In this stage the person functions normally, has no memory loss, and is mentally healthy. People with NO dementia would be considered to be in Stage 1.  |
| No Dementia | Stage 2<br>Very Mild Cognitive Decline         | This stage is used to describe normal forgetfulness associated with aging; for example, forgetfulness of names and where familiar objects were left. Symptoms are not evident to loved ones or the physician.  |
| No Dementia | Stage 3<br>Mild Cognitive Decline              | This stage includes increased forgetfulness, slight difficulty concentrating, decreased work performance. People may get lost more often or have difficulty finding the right words. At this stage, a person's loved ones will begin to notice a cognitive decline. Average duration: 7 years before onset of dementia   |
| Early-Stage | Stage 4<br>Moderate Cognitive Decline          | This stage includes difficulty concentrating, decreased memory of recent events, and difficulties managing finances or traveling alone to new locations. People have trouble completing complex tasks efficiently or accurately and may be in denial about their symptoms. They may also start withdrawing from family or friends because socialization becomes difficult. At this stage, a physician can detect clear cognitive problems during a patient interview and exam. Average duration: 2 years |
| Mid-Stage   | Stage 5<br>Moderately Severe Cognitive Decline | People in this stage have major memory deficiencies and need some assistance to complete their daily activities (dressing, bathing, preparing meals). Memory loss is more prominent and may include major relevant aspects of current lives; for example, people may not remember their address or phone number and may not know the time or day or where they are. Average duration: 1.5 years  |



|            |  |   |
|------------|--|---|
| Mid-Stage  | Stage 6<br>Severe Cognitive<br>Decline<br>(Middle Dementia)    | People in Stage 6 require extensive assistance to carry out daily activities. They start to forget names of close family members and have little memory of recent events. Many people can remember only some details of earlier life. They also have difficulty counting down from 10 and finishing tasks. Incontinence (loss of bladder or bowel control) is a problem in this stage. Ability to speak declines. Personality changes, such as delusions (believing something to be true that is not), compulsions (repeating a simple behavior, such as cleaning), or anxiety and agitation may occur. Average duration: 2.5 years |
| Late-Stage | Stage 7<br>Very Severe Cognitive<br>Decline<br>(Late Dementia) | People in this stage have essentially no ability to speak or communicate. They require assistance with most activities (e.g., using the toilet, eating). They often lose psychomotor skills, for example, the ability to walk. Average duration: 2.5 years  |

---

Reisberg, Ferris, de Leon, & Crook, 1988

## Appendix C: Clinical Dementia Rating Scale



INITIAL VISIT PACKET NACC UNIFORM DATA SET (UDS)

## Form B4: Global Staging—Clinical Dementia Rating (CDR) STANDARD AND SUPPLEMENTAL

ADC name: \_\_\_\_\_ Subject ID: \_\_\_\_\_ Form date: \_\_\_\_/\_\_\_\_/\_\_\_\_ Visit #: \_\_\_\_\_ Examiner's initials: \_\_\_\_\_

**INSTRUCTIONS:** For information on the required online CDR training, see UDS Coding Guidebook for Initial Visit Packet, Form B4. This form is to be completed by the clinician or other trained health professional, based on co-participant report and behavioral and neurological exam of the subject. In the extremely rare instances when no co-participant is available, the clinician or other trained health professional must complete this form using all other available information and his/her best clinical judgment. Score only as decline from previous level due to cognitive loss, not impairment due to other factors, such as physical disability. For further information, see UDS Coding Guidebook for Initial Visit Packet, Form B4.

SECTION 1: STANDARD CDR<sup>1</sup>Please enter  
score below:

|  | IMPAIRMENT   |   |   |  |  |
|--|--|---|---|--|--|
|  | None — 0   | Questionable — 0.5  | Mild — 1  | Moderate — 2   | Severe — 3   |
| 1. Memory<br>_____                       | No memory loss, or slight inconsistent forgetfulness   | Consistent slight forgetfulness; partial recollection of events; "benign" forgetfulness | Moderate memory loss, more marked for recent events; defect interferes with everyday activities                                     | Severe memory loss; only highly learned material retained; new material rapidly lost                                       | Severe memory loss; only fragments remain  |
| 2. Orientation<br>_____                  | Fully oriented   | Fully oriented except for slight difficulty with time relationships                     | Moderate difficulty with time relationships; oriented for place at examination; may have geographic disorientation elsewhere        | Severe difficulty with time relationships; usually disoriented to time, often to place                                     | Oriented to person only  |
| 3. Judgment and problem solving<br>_____ | Solves everyday problems, handles business and financial affairs well; judgment good in relation to past performance | Slight impairment in solving problems, similarities, and differences                    | Moderate difficulty in handling problems, similarities, and differences; social judgment usually maintained                         | Severely impaired in handling problems, similarities, and differences; social judgment usually impaired                    | Unable to make judgments or solve problems   |
| 4. Community affairs<br>_____            | Independent function at usual level in job, shopping, volunteer and social groups                                    | Slight impairment in these activities   | Unable to function independently at these activities, although may still be engaged in some; appears normal to casual inspection    | No pretense of independent function outside the home; appears well enough to be taken to functions outside the family home | No pretense of independent function outside the home; appears too ill to be taken to functions outside the family home |
| 5. Home and hobbies<br>_____             | Life at home, hobbies, and intellectual interests well maintained  | Life at home, hobbies, and intellectual interests slightly impaired                     | Mild but definite impairment of function at home; more difficult chores abandoned; more complicated hobbies and interests abandoned | Only simple chores preserved; very restricted interests, poorly maintained   | No significant function in the home  |
| 6. Personal care<br>_____.0              | Fully capable of self-care (= 0).  |   | Needs prompting   | Requires assistance in dressing, hygiene, keeping of personal effects  | Requires much help with personal care; frequent incontinence   |
| 7. _____                                 | STANDARD CDR SUM OF BOXES  |   |   |  |  |
| 8. _____                                 | STANDARD GLOBAL CDR  |   |   |  |  |

<sup>1</sup>Morris JC. The Clinical Dementia Rating (CDR): Current version and scoring rules. *Neurology* 43(11):2412-4, 1993. Copyright© Lippincott, Williams & Wilkins. Reproduced by permission.

Subject ID: \_\_\_\_\_

Form date: \_\_\_\_/\_\_\_\_/\_\_\_\_

Visit #: \_\_\_\_\_

**INSTRUCTIONS:** For information on the required online CDR training, see UDS Coding Guidebook for Initial Visit Packet, Form B4. This form is to be completed by the clinician or other trained health professional, based on co-participant report and behavioral and neurological exam of the subject. In the extremely rare instances when no co-participant is available, the clinician or other trained health professional must complete this form using all other available information and his/her best clinical judgment. Score only as decline from previous level due to cognitive loss, not impairment due to other factors, such as physical disability. For further information, see UDS Coding Guidebook for Initial Visit Packet, Form B4.

## SECTION 2: SUPPLEMENTAL CDR

Please enter  
score below:

|   | IMPAIRMENT   |   |   |   |   |
|---|--|---|---|---|---|
|   | None — 0   | Questionable — 0.5  | Mild — 1  | Moderate — 2  | Severe — 3  |
| <b>9. Behavior, comportment, and personality<sup>2</sup></b><br>_____ | Socially appropriate behavior                                | Questionable changes in comportment, empathy, appropriateness of actions  | Mild but definite changes in behavior   | Moderate behavioral changes, affecting interpersonal relationships and interactions in a significant manner                                     | Severe behavioral changes, making interpersonal interactions all unidirectional |
| <b>10. Language<sup>3</sup></b><br>_____                              | No language difficulty, or occasional mild tip-of-the-tongue | Consistent mild word-finding difficulties; simplification of word choice; circumlocution; decreased phrase length; and/or mild comprehension difficulties | Moderate word-finding difficulty in speech; cannot name objects in environment; reduced phrase length and/or agrammatical speech and/or reduced comprehension in conversation and reading | Moderate to severe impairments in either speech or comprehension; has difficulty communicating thoughts; writing may be slightly more effective | Severe comprehension deficits; no intelligible speech                           |

<sup>2</sup>Excerpted from the Frontotemporal Demential Multicenter Instrument & MR Study (Mayo Clinic, UCSF, UCLA, UW).

<sup>3</sup>Excerpted from the PPA-CDR: A modification of the CDR for assessing dementia severity in patients with primary progressive aphasia (Johnson N, Weintraub S, Mesulam MM), 2002.

## Appendix D

## Functional Assessment Staging (FAST)

| FAST Stage and Characteristics  | Clinical Diagnosis  | Duration of stage* |
|---|---|--------------------|
| 1. No functional decrement  | Normal Adult  | 50 years           |
| 2. Subjective word difficulties   | Normal Aged Adult   | 15 years           |
| 3. Decreased function in demanding employment settings                                      | Compatible with possible incipient Alzheimer's disease in minority of cases | 7 years            |
| 4. Decreased ability to handle complex tasks such as finances or planning dinner for guests | Mild Alzheimer's disease  | 2 years            |
| 5. Requires assistance in choosing proper clothing  | Moderate Alzheimer's disease  | 18 months          |
| 6. a) difficulty dressing properly  | Moderately severe Alzheimer's disease                                       | 5 months           |
| b) requires assistance bathing  |   | 5 months           |
| c) inability to handle mechanics of toileting   |   | 5 months           |
| d) urinary incontinence   |   | 4 months           |
| e) fecal incontinence   |   | 10 months          |
| 7. a) ability to speak limited to about six words   | Severe Alzheimer's disease  | 12 months          |
| b) intelligible vocabulary limited to single word   |   | 18 months          |
| c) ambulatory ability lost  |   | 12 months          |
| d) ability to sit up lost   |   | 12 months          |
| e) ability to smile lost  |   | 18 months          |
| f) ability to hold head up lost   |   | Not applicable     |

*\*duration of stage in those entering the stage who progress into the next stage; not all patients progress.*

Sclan & Reisberg, 1992

## Appendix E: Institutional Review Board Approval Form and Completion of Course in the Protection of Human Research Subjects (CITI)



**Revised Letter (August 9, 2016)**

**DATE:** July 25, 2016

**TO:** Richard Fortinsky, Ph.D.  
Center on Aging  
UConn Health

Elena Schjavland, Student Researcher  
Sociology

**FROM:** Diana Sobieraj, Pharm.D. *DS*  
Institutional Review Board Member  
FWA #00007125

**RE:** Protocol #: H16-133 "Heart and Soul: A Phenomenology of Dementia Spouse Caregivers' Relationship Closeness"  
*Please refer to the Protocol# in all future correspondence with the IRB.*  
Funding Source: Investigator Out-of-Pocket  
**Approval Period: From: July 25, 2016 Valid Through: July 25, 2017**  
"Expiration Date"

On June 30, 2016, the Institutional Review Board (IRB) reviewed the above-referenced research study by expedited review and determined that modifications were required to secure approval. Those requirements have been met, and the IRB granted approval of the study on July 25, 2016. The research presents no more than minimal risk to human subjects and qualifies for expedited approval under category # 7 - Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Enclosed is the validated consent form, which is valid through July 25, 2017. **A copy of the approved, validated and stamped consent form (with the IRB's stamp) must be used to consent each subject. Copies of the approved, validated and stamped recruitment material must also be used. The IRB did not validate the folding post-card mailer but its use is approved.**

For the telephone screening, per 45 CFR 46.117(c)(2), the IRB waived the requirement for the investigator to obtain a signed consent form for the subjects because it found that the research presents no more than minimal risk of harm to subjects and involves no procedures for which written consent is normally required outside of the research context.

Office of the Vice President for Research  
**Research Compliance Services**  
438 WHITNEY ROAD EXTENSION, UNIT 1248  
STORRS, CT 06269-1248  
PHONE 860.486.8802  
FAX 860.486.1044  
compliance.uconn.edu

*An Equal Opportunity Employer*



All investigators at the University of Connecticut are responsible for complying with the attached IRB "Responsibilities of Research Investigators."

Re-approval: It is the investigator's responsibility to apply for re-approval of ongoing research at **least once yearly**, or more often if specified by the IRB. The Re-approval/Completion Form (IRB-2) and other applicable re-approval materials must be submitted **one month** prior to the expiration date noted above.

Modifications: If you wish to change any aspect of this study, such as the procedures, the consent forms, the investigators, or funding source, please submit the changes in writing to the IRB using the Amendment Review Form (IRB-3). All modifications must be reviewed and approved by the IRB prior to initiation.

Audit: All protocols approved by the IRB may be audited by the Research Compliance Monitor.

*Please keep this letter with your copy of the approved protocol.*

Attachments:

1. Validated Consent Form
2. Validated Recruitment Material
3. Validated Appendix A
4. Validated IRB-1 Application and Study Protocol Forms
5. "Responsibilities of Research Investigators"

[English](#)Text size: [A](#) [A](#)Elena Schjavid ID: 692294 | [Log Out](#) | [Help](#)[Search Knowledge Base](#)[Main Menu](#) | [My Profiles](#) | [My CEUs](#) | [My Reports](#) | [Support](#)[Main Menu](#) » [My Profiles](#)**Success: Your information has been successfully submitted.**

## CITI Program Profile

First Name: Elena

Last Name: Schjavid

[Change my name](#)

Username: els07011

Password: \*\*\*\*\*

[Change my password](#)

Preferred Email: elena\_mystic@msn.com

Secondary Email:

[Change my email address](#)

Security Question: What color was your first car?

[Change my security question & answer](#)

Show CE credit information when available: No

CE credit types: N/A

[Change my CE credit preferences](#)

Participate in research surveys: No

[Change my research survey preference](#)

Gender:

Ethnicity:

Race:

[Change my gender, race, or ethnicity](#)

Country of Residence: Ethiopia

[Change my country of residence](#)

Member ID: 692294

Member Since: 09/25/2007

Last Profile Update: 09/25/2007

## University of Connecticut - Storrs &amp; Regional Campuses Profile

## Appendix F: Depression Symptoms and Local Support Group Information Document

### Dementia Caregiver

#### Support & Groups

Alzheimer's Association  
19 Ohio Avenue  
Norwich, CT 06360  
860-887-3593

#### Bereavement & Grief Support Services

Catholic Charities Office  
331 Main Street  
Norwich, CT 06360  
860-889-8346 ext. 260

Center for Hospice Care  
227 Dunham Street  
Norwich, CT 06360  
860-848-5699

### Signs and Symptoms of Depression

- Difficulty Sleeping or Sleeping Too Much
- Difficulty Concentrating
- Feeling of Hopelessness or Helplessness
- Overwhelming and Uncontrollable Negative Thoughts
- Loss of Appetite or Significant Increase in Appetite
- Increase in Irritability, Aggression or Anger
- Increase in Alcohol Consumption and/or Reckless Behavior

### How to Tell Your Doctor or PCP You're Depressed

If you have been experiencing feelings of sadness and emptiness that have lasted more than a few weeks or months, you may be facing depression. The only way to get a definitive diagnosis is to visit your doctor or PCP for a complete evaluation. It is important to understand the basic signs and symptoms of depression and be willing to open up to your doctor about what you have been experiencing.

Step 1. Recognize the symptoms of depression.

Step 2. Set up an appointment. Make sure your appointment includes enough time for you to be able to explain all of your symptoms and concerns.

Step 3. Explain all of your symptoms. Describe your stress and responsibilities as a dementia caregiver. You may want to create a journal or jot down symptoms in a notebook. Write the time and date when you have symptoms and if there are any particular triggers leading to your symptoms. Don't hold back how you feel; you want your doctor to be able to offer you the best form of treatment for your type of depression.

Step 4. Mention any underlying illness or non-depression related symptoms. It is important to talk about your overall health when talking with your doctor. Don't be afraid to tell him about anxiety symptoms, aches and pains, gastrointestinal problems or issues with your joints or skin. Some symptoms may indicate a disease that could trigger your depression symptoms and they need to be treated accordingly.

Step 5. Speak honestly about thoughts of harming yourself. Don't be ashamed to tell your doctor about any suicidal thoughts or attempts. He may immediately guide you to get one-on-one help that could save your life.



## Appendix G: Recruitment Marketing Material



*When we said our wedding vows:  
to love, honor and cherish...  
Alzheimer's was the last  
thing on our minds.*



### **Heart and Soul: A Study of Dementia Spouse Caregivers' Relationship Closeness**

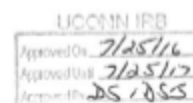
*Study will enroll participants from August 2016 – December 2016*

Volunteers are invited to join a University of Connecticut research project studying the relationship between married couples when one spouse has a memory disease, dementia or Alzheimer's.

- Your husband or wife must have a memory disease, dementia or Alzheimer's. He or she must be over 65 years of age.
- Couples must live together in a house, apartment, or assisted-living residence in New London County/Southeast CT or Westerly-Providence, RI communities.
- **You** as a caregiver will be asked to describe your marriage closeness in relation to the dementia and behavior symptoms your spouse has now.
- Your interview is scheduled at a time you choose; it can be in your home, a place that is convenient for you, or in a Groton Senior Center office.
- It may take 60 minutes or more.  
Your personal information is kept secret.
- Participants will receive a \$15 gift card to a local grocery store or pharmacy.

*This research study is to support my Doctoral Dissertation at The University of Connecticut School of Nursing, and is conducted under the direction of Dr. R. Fortinsky, Ph.D. at the UConn Center on Aging.*

For more information contact me:  
Elena Schjavidland, Nurse Practitioner, PhD(c)  
Phone: 860-501-4095  
Email: SpouseStudy@msn.com



Elena Schjaland  
 c/o Keys2Memory®  
 23 East Main Street  
 PO Box 625  
 Mystic, CT 06355-7728

Please  
 place first  
 class stamp  
 here

*When we said our wedding vows:  
 to love, honor and cherish...  
 Alzheimer's was the last thing on our minds.*



**If your spouse has a  
 memory disease, dementia  
 or Alzheimer's, you are  
 invited to participate in a  
 research study.**



This research study is in support of my Doctoral Dissertation, at The University of Connecticut School of Nursing, under the direction of Dr. R. Fortinsky, Ph.D. at the UConn Center on Aging.

### Heart and Soul: A Phenomenology of Dementia Spouse Caregivers' Relationship Closeness

Volunteers are invited to join a University of Connecticut research project studying the relationship between married couples when one spouse has a memory disease, dementia or Alzheimer's.

*Study will enroll participants from June 2016 – October 2016*

- Your husband or wife must have a memory disease, dementia or Alzheimer's.
- Couples must live together in a house, apartment, or assisted-living residence in New London County/Southeast CT or Westerly-Providence, RI communities.
- You as a caregiver will be asked to describe your marriage in relation to the dementia and behavior symptoms your spouse has now
- Your interview is scheduled at a time you choose; it can be in your home, a place that is convenient for you, or the Groton Senior Center.
- It may take 60 minutes or more. Your personal information is kept secret.
- Participants will receive a \$15 gift card to a local grocery store or pharmacy.



For more information mail this card, or contact me:

Elena Schjavad, Nurse Practitioner - PhD(c)

Phone: 860-501-4095

Email: SpouseStudy@msn.com

IRB

detach here

☐ I may be interested in participating in this study.

☐ Call me.

☐ Email me.

☐ Send me information by mail.

Name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Phone: \_\_\_\_\_

Email: \_\_\_\_\_



Appendix H: Participant General Appointment Information;  
Consent Form and Competency to Consent Form.

HEART AND SOUL: A Phenomenology of Dementia Spouse Caregivers' Relationship Closeness

Phone Screening Eligibility

Eligibility Criteria

|                            |   |                             |
|----------------------------|---|-----------------------------|
| Age of dementia spouse >65 | YES <input type="checkbox"/>            | NO <input type="checkbox"/> |
| Spouse caregiver           | YES <input type="checkbox"/>            | NO <input type="checkbox"/> |
| English speaking           | YES <input type="checkbox"/>            | NO <input type="checkbox"/> |
| Southeast CT community     | YES <input type="checkbox"/>            | NO <input type="checkbox"/> |
| Co-resides with spouse     | YES <input type="checkbox"/>            | NO <input type="checkbox"/> |
| Dementia Diagnosed by      | PGP <input type="button" value="v"/>    |                             |
| How long ago               | <input type="text"/>                    |                             |
| Dementia type              | Other: <input type="button" value="v"/> |                             |

Caregiver Name:

Phone #  email:

Address

Appointment date:

Time:

Place:

Client ID:

Comments:

Initials

Date

## Consent Form for Participation in a Research Study



**Principal Investigator:** Richard Fortinsky, Ph.D.

**Student Researcher:** Elena Schjavland, Ph.D.(c)

**Study Title:** Heart and Soul: A Phenomenology of Dementia Spouses' Relationship Closeness

### Introduction

You are invited to join a research study to examine the emotional bond between married couples when one spouse has a memory disease, dementia or Alzheimer's. You are being asked to participate because you are a caregiver of a spouse with a memory disease, speak English, live together with your husband or wife, and reside in the Southeast Connecticut or Southwest Rhode Island communities.

This consent form will give you the information you will need to understand why this study is being done and why you are being invited to participate. It will also describe what you will need to do to participate, and any known risks, inconveniences or discomforts that you may have while participating. We encourage you to take some time to think this over and to discuss it with your family, friends, and doctor. We also invite you to ask questions now and at any time. If you decide to participate, you will be asked to sign this form, and it will be a record of your agreement to participate. You will be given a copy of this form.

### Why is this study being done?

Communication, affection and shared activities between couples play an important part in marriage. That sometimes changes when a spouse has a chronic illness. The purpose of this research study is to understand better how you describe your feelings towards your spouse now that they have a memory disease, dementia or Alzheimer's. As part of my doctoral dissertation, I am conducting this study to offer a clearer understanding of the description of relationship closeness from your point of view. So in the future, we can define it accurately, measure it more effectively, and be sensitive to any changes.

### What are the study procedures? What will I be asked to do?

As a potential participant, you will be screened to be able to participate. For inclusion, you must be married to a person with memory disease, dementia or Alzheimer's. You must speak English. You must live in the community, and your spouse must live with you— not in a residence, rehab or long term care facility. It is OK to have family, friends or paid helping caregivers. If you agree to take part in this study, you will be asked to review and sign the consent; you will be interviewed, and tape recorded, and lastly complete a simple, very general demographics form.

You will be asked to describe the feelings you have about your relationship closeness with your spouse now that they have symptoms of dementia. The interview will not include any specific sexual questions, although you can discuss intimacy if you would like. In order to participate, you must agree to be audio recorded.

The recorded interview will be conducted at a time and place of your choosing. It can be at your home, the Groton Senior Citizen Center (102 Newtown Rd, Groton, CT 06340), or another other mutually agreed on place or setting. It can be scheduled Monday through Sunday, between 8AM and 7PM. The research project may require as much one to two hours of your time.

At some point you may be contacted to clarify statements, comment on overall study findings, or be asked your opinion of study results. You do not have to participate in these follow up interviews. If you elect to receive follow up information pertaining to the study results, publication or outcomes, the researcher will provide you those outcomes. You will be contacted by your requested format: mail, phone or email. You can communicate with the student researcher, Elena Schjavland, at any time after the study is complete with questions or comments.

### What are the risks or inconveniences of the study?

Sometimes speaking about dementia symptoms, the progressive nature of dementia disease and the changes it has caused in the marriage, can cause emotional upset, sadness, and grief. Speaking of these feelings can also be helpful and therapeutic, too. There is information available for dementia caregiver support groups and grief and bereavement groups if you desire. We believe there are no known physical or health risks associated with this research study. An inconvenience may be the time it takes to complete the interview.

### What are the benefits of the study?

You may not directly benefit from this research; however, we hope that your participation in the study may provide valuable information to the dementia research community in their mission to examine and study the family caregiver as an important and integral member of the health care and caregiving team.

### Will I receive payment for participation? Are there costs to participate?

There are no costs to you to take part in this study. Upon conclusion of the tape recorded interview, you will be given a gift card in the amount of fifteen dollars (\$15). Gift cards are available for a grocery store or pharmacy of your choice. You will also receive the book: "Caring for a Person with Alzheimer's Disease" (National Institute on Aging, 2016), an easy to use guide available in print from the Alzheimer's Disease Education and Referral (ADEAR) Center.

### How will my personal information be protected?

The following procedures will be used to protect the confidentiality of your data.

The researchers will keep all study records (including any codes to your data) and hard-drive locked in a secure location. Files and data will be coded with a sequence number derived from a number that reflects how many people have enrolled in the study, and any direct quotes from participants recorded in the findings will be coded with a pseudonym. A master key that links names, pseudonyms and codes will be maintained in a separate and secure location. The master key and audiotapes will be destroyed after 3 years. All electronic files (e.g., database, spreadsheet, etc.) containing identifiable information will be password protected. Any computer hosting such files will also have password protection to prevent access by unauthorized users. Only the members of the research staff will have access to the passwords. Data that will be shared with others will be coded as described above to help protect your identity. At the conclusion of this study, the researchers may publish their findings. Information will be presented in a summary format, and you will not be identified in any publications or presentations. We will do our best to protect the confidentiality of the information we gather from you but we cannot guarantee 100% confidentiality

You should also know that the UConn Institutional Review Board (IRB) and Research Compliance Services may inspect study records as part of its auditing program, but these reviews will only focus on the researchers and not on your responses or involvement. The IRB is a group of people who review research studies to protect the rights and welfare of research participants.

### Can I stop being in the study and what are my rights?

You do not have to be in this study if you do not want to. If you agree to be in the study, but later change your mind, you may drop out at any time. There are no penalties or consequences of any kind if you decide that you do not want to participate. Also, you do not have to answer any individual question, or questions, that you do not want to answer.



### Whom do I contact if I have questions about the study?

Take as long as you like before you make a decision. We will be happy to answer any question you have about this study. If you have further questions about this study or if you have a research-related problem, you may contact the principal investigator, (Dr. R. Fortinsky) or the student researcher (Elena Schjavland: 860-501-4095, or email: spousestudy@msn.com). If you have any questions concerning your rights as a research participant, you may contact the University of Connecticut Institutional Review Board (IRB) at 860-486-8802.

### **Documentation of Consent:**

I have read this form and decided that I will participate in the project described above. Its general purposes, the of involvement and possible risks and inconveniences have been explained to my satisfaction. I understand that I can withdraw at any time. My signature also indicates that I have received a copy of this consent form.

X  
Participant Signature:

\_\_\_\_\_  
Print Name:

11/15/2016  
Date:

\_\_\_\_\_  
Signature of Person  
Obtaining Consent

Elena Schjavland  
Print Name:

11/15/2016  
Date:

## Research Study Audio Release Form



**Principal Investigator:** Richard Fortinsky, Ph.D.

**Student Researcher:** Elena Schjavland, Ph.D.(c)

**Study Title:** Heart and Soul: A Phenomenology of Dementia Spouse Caregivers' Relationship Closeness

As part of this research study, the University of Connecticut and those acting pursuant to its authority ("UCONN") may record your voice on a particular medium ("recordings") including digital, and electronic mediums during your participation in this research study. Please indicate what uses of these recordings you are willing to permit, by putting your initials next to the uses you agree to and signing the form at the end. The choice is entirely up to you. We will only use recordings in the ways that you agree to. In any recording, you will not be identified by name. The recordings will not be used for commercial purposes.

1. \_\_\_\_\_ The recordings can be studied by the research team for use in the research project
2. \_\_\_\_\_ The recordings can be used for scientific publications
3. \_\_\_\_\_ The recordings can be used for scientific conferences or meetings
4. \_\_\_\_\_ The recordings can be used for educational purposes
5. \_\_\_\_\_ The recordings can be used for public presentations to non-scientific groups
6. \_\_\_\_\_ The recordings can be used on television or the audio portion can be used on radio
7. \_\_\_\_\_ The recordings can be posted to a UCONN website
8. \_\_\_\_\_ The recordings can be used for reports/presentations to any research funding agencies
9. \_\_\_\_\_ The recordings can be used for all the above purposes.

I understand that all such recordings, in whatever medium, shall remain the property of UCONN. My name will not be used in any publication. I agree that I will not be compensated for the use of the recordings. I have read the above descriptions and give my consent for the use of the recordings as indicated by my initials above.

X  
\_\_\_\_\_  
Participant Signature:

\_\_\_\_\_  
Print Name:

\_\_\_\_\_  
Date:

\_\_\_\_\_  
Signature of Person  
Obtaining Consent

Elena Schjavland  
\_\_\_\_\_  
Print Name:

\_\_\_\_\_  
Date:

## Consent and Capacity Screening

Participant can articulate:

- |   |  |
|---|--|
| 1. The purpose of the study               | <input type="checkbox"/> YES <input type="checkbox"/> NO |
| 2. That the study is voluntary            | <input type="checkbox"/> YES <input type="checkbox"/> NO |
| 3. Participant confidentiality            | <input type="checkbox"/> YES <input type="checkbox"/> NO |
| 4. Research personnel contact information | <input type="checkbox"/> YES <input type="checkbox"/> NO |

Client ID:

Comments:

## Study Participant Demographics

Client ID#

**Caregiver****Care-recipient**

Age

Sex

Race

Culture/Ethnicity

Religion

Years of Education

Occupation

**Current Marriage**1<sup>st</sup>, 2<sup>nd</sup>, 3<sup>rd</sup>1<sup>st</sup>, 2<sup>nd</sup>, 3<sup>rd</sup>

Age when married

# Years married

Income:

Housing:

## Appendix I: Phenomenal Study Data Control NVIVO Nodes

## Nodes

| Name                                 | Sources | References |
|--------------------------------------|---------|------------|
| 0. The backstory Who we were         | 11      | 29         |
| Who my spouse was                    | 8       | 15         |
| 1. I see the dementia...             | 16      | 140        |
| Dementia Symptoms                    | 16      | 90         |
| Anxiety activating                   | 10      | 24         |
| Confusion - Circadian Rhythm - Psych | 5       | 9          |
| Mood swings                          | 4       | 4          |
| OCD                                  | 1       | 1          |
| Behaviors                            | 9       | 16         |
| anosognosia                          | 1       | 1          |
| Egocentric                           | 3       | 3          |
| hoarding                             | 1       | 1          |
| Self-Neglect                         | 3       | 4          |
| shadowing                            | 5       | 5          |
| wandering                            | 2       | 2          |
| Cognition                            | 15      | 30         |
| Executive loss                       | 7       | 10         |
| Memory                               | 12      | 13         |
| Speech Language                      | 5       | 7          |
| Passivity apathy depression          | 10      | 20         |
| Slowness                             | 1       | 1          |
| Functional decline                   | 14      | 32         |
| apraxia                              | 1       | 1          |
| Forfeiture of Driving                | 5       | 7          |
| Hearing Loss                         | 2       | 2          |
| Incontinence                         | 2       | 2          |
| Mobility and balance                 | 5       | 6          |
| poor appetite                        | 1       | 1          |
| Sexuality                            | 1       | 1          |
| social Isolation                     | 8       | 11         |
| Story of Dementia Onset              | 10      | 17         |

## Nodes

| Name  | Sources | References |
|---|---------|------------|
| Understand and not-understanding deme       | 7       | 10         |
| 2. I feel the dementia ...                  | 16      | 127        |
| AGAPE Love and Tenderness                   | 16      | 63         |
| Cherished Moments                           | 9       | 17         |
| RC  | 15      | 32         |
| Distance                                    | 1       | 1          |
| Time together                               | 2       | 2          |
| Communication - sounds and silence          | 16      | 39         |
| interpreting what they are trying to say or | 11      | 16         |
| Loss and hurt                               | 11      | 25         |
| activities                                  | 3       | 4          |
| Meals                                       | 5       | 6          |
| sleep                                       | 1       | 1          |
| 3. I respond to the dementia ...            | 16      | 218        |
| Advocacy                                    | 15      | 64         |
| changes and unpredictable                   | 9       | 16         |
| Parenting the spouse                        | 8       | 14         |
| Protective watchful                         | 12      | 28         |
| leaving them ALONE                          | 5       | 5          |
| Vows loyalty allegiance                     | 4       | 6          |
| Being kind                                  | 8       | 12         |
| Humor                                       | 7       | 8          |
| I'm not perfect                             | 12      | 25         |
| Clean Slate - Tabula Rasa                   | 3       | 4          |
| Keeping the scale balanced                  | 16      | 109        |
| Coping                                      | 14      | 47         |
| Control vs. flexibility                     | 9       | 21         |
| exercise                                    | 3       | 6          |
| reminisce                                   | 2       | 2          |
| respite                                     | 2       | 3          |

## Nodes

| ✚ | Name  | Sources | References |
|---|---|---------|------------|
| ✚ | <ul style="list-style-type: none"> <li data-bbox="456 422 475 447">✚</li> <li data-bbox="456 447 475 472">✚</li> </ul>  | 4       | 5          |
| ✚ | <ul style="list-style-type: none"> <li data-bbox="456 447 475 472">✚</li> <li data-bbox="456 472 475 497">✚</li> </ul>  | 7       | 9          |
| ✚ | <ul style="list-style-type: none"> <li data-bbox="456 497 475 522">✚</li> <li data-bbox="456 522 475 548">✚</li> <li data-bbox="456 548 475 573">✚</li> </ul> | 7       | 14         |
| ✚ | <ul style="list-style-type: none"> <li data-bbox="456 522 475 548">✚</li> <li data-bbox="456 548 475 573">✚</li> </ul>  | 8       | 15         |
| ✚ | <ul style="list-style-type: none"> <li data-bbox="456 548 475 573">✚</li> <li data-bbox="456 573 475 598">✚</li> </ul>  | 13      | 30         |
| ✚ | <ul style="list-style-type: none"> <li data-bbox="456 598 475 623">✚</li> <li data-bbox="456 623 475 648">✚</li> <li data-bbox="456 648 475 674">✚</li> </ul> | 11      | 18         |
| ✚ | <ul style="list-style-type: none"> <li data-bbox="456 623 475 648">✚</li> <li data-bbox="456 648 475 674">✚</li> </ul>  | 7       | 7          |
| ✚ | <ul style="list-style-type: none"> <li data-bbox="456 648 475 674">✚</li> <li data-bbox="456 674 475 699">✚</li> </ul>  | 5       | 5          |
| ✚ | <ul style="list-style-type: none"> <li data-bbox="456 699 475 724">✚</li> <li data-bbox="456 724 475 749">✚</li> </ul>  | 14      | 28         |
| ✚ | <ul style="list-style-type: none"> <li data-bbox="456 749 475 774">✚</li> <li data-bbox="456 774 475 800">✚</li> </ul>  | 6       | 10         |

## Appendix J

**Representative Sample of Relevant Statements and Formulated Meanings.**

| Theme 1: A history together  |  |
|--|--|
| Relevant Statements<br>Extracted from Original Protocols   | Formulated Meanings  |
| We both had had spouses and lost them and so we didn't like being alone very much and so when we just were kind of clicking, and in love, and it felt right. I think that he was on the erudite side— <i>is that the word?</i> — scholarly, he was always teaching and he always has been in the administration...had run schools...he had written a little book, and I have a copy of it. | The relationship originated from common needs and a pragmatism as well as a desirability based on emotions of love and attraction to intelligence.   |
| When we were first married, we would go and do and not think about it's too late to drive. And we'd just talk about things that we did. We did an awful lot with the kids.   | There was spontaneity, commonality, shared activities and meaningful communication in the marriage.  |
| He was into bird watching so he definitely would be out walking a lot. And then he also would run in races so he was out doing that kind of thing, a lot walking and doing. And whenever he would have me with him, I mean I always was there with him, by watching him in the races, and so being there for him when he came in... that kind of thing, you know.                          | Athleticism, physical activity and hobbies were an important part of couplehood where each spouse could be autonomous, yet join together for mutual support.                                 |
| He was in the choir and I was in the choir because of him. And that was a connection.  | A reciprocal activity was initiated with the goal of enjoying a mutual interest.   |
| She's very intelligent. We're both engineers. One time we got partnered together for computer programming because we were taking the same course. We learned we don't think alike!   | His spouse was intelligent; and marriage was a learning environment in which there were contrasts.   |
| We met in high school and he's always been really... like I said, my protector, he's always been right there for me. We have always worked together on things. I wouldn't even buy a chair without talking to him about it and saying what do you think do we need this chair, you know, this kind of thing.   | The relationship was based on feelings of trust, open dialog and commitment.   |
| There was a real heartfelt intimacy. He'd understand me, understand where I was coming from, not just put up with why I did this or why I made this decision, but whether he agreed with me or not, at least have an understanding of it and vice-versa.   | Meta cognition, specifically empathy and understanding, was an assumption to maintain the relationship.  |
| He depended on me, I depended on him   | Interdependence framed the marriage.   |
| Theme 2a. I see the dementia: We have a dementia story   |  |
| Relevant Statements<br>Extracted from Original Protocols   | Formulated Meanings  |
| He was president of the senior citizen's board for a number of years. They gave him a certificate. Because they realized he was having some trouble I think. I have to show it to you. It's on the wall. I put it in... I framed it. This is it.   | Realization that dementia was present and was noted by people outside the family as well. The contrast of how it "used to be" is important and objectified with a commemorative certificate. |



He really wasn't taking care of himself in the sense that he wasn't taking his medication correctly.

We had to call Triple A at 10:30 at night; we went out for dinner at friends and we were still an hour away; we hit curbing and I knew something was wrong with the tires and we were lost and I couldn't make out the directions. And we came up on a police station, I went in to get help. The tire was shredded. From then on, I took over driving.

When at the end of three accidents and then when he drove right through the garage and out the back...I was with him! And we had to see a neurologist and the neurologist did all kinds of tests and that said...the disappointment was there!

We were at a college scholars program. He taught there and has his doctorate; he's smart and was always in charge. It was so embarrassing at dinner he just talked on and on and didn't make any sense. I could see people getting restless, they didn't know how to stop him. They were so polite at the table and I just tried to gently get one of the others talking so we could make our goodbyes.

He had an accident a little over a year ago, just a fender bender, but it was enough for me to say that's it. There will be no more driving, and I never say to him you can't drive, meaning you don't have the ability to. I said you know how to drive. It's just that it's not recommended that you drive. The doctors don't want you driving the car based on the medication that you take and your mental capacity because if you say to somebody you can't drive, can't means you don't have the ability to ...in his mind.

Memory and neglect were identified as the precipitating symptoms.

Seminal story recalled of a frightening experience as an initiation to dementia diagnosis; there was realization of how dementia physically changed lifestyle.

Pivotal story illustrating the fear and safety dementia symptoms trigger and then the awareness of positive diagnosis and resulting emotions.

Dementia diagnosis was known to family and in this event, symptoms were revealed to colleagues and friends.

The dementia disease diagnosis is recognized but is suppressed; and medicalized reasons for the driving restriction are employed. The caregiver is providing an alternative truth to acknowledge the disease yet preserve dignity, self-esteem and locus of control to her husband the care-recipient.

## Theme 2b. I see the dementia: Naming the symptoms

| Relevant Statements<br>Extracted from Original Protocols  | Formulated Meanings  |
|---|--|
| ...the forgetfulness almost like he doesn't really forget I am here, but there is that sense that... he sort-of does.                         | Cognitive impairment symptom of amnesia was recognized.                              |
| She was a brilliant woman. She was so much smarter than me!   | Contrast of before and after disease cognitive losses were identified.               |
| You know, he doesn't have dementia in his mind, you know, so that's the hard part. You know, he doesn't understand what his issues have been. | Cognitive impairment symptom of anosognosia was recognized.                          |
| Little reminders for her that the dish by the sink is, has pills in it.   | Memory loss is identified as a problem in maintenance of activities of daily living. |
| He's a compulsive shopper and a compulsive purchaser, and the paranoia!   | NPS symptoms of repetitive behavior and delusions were recognized.                   |

|  |   |
|--|---|
| ...he has a lot of anxiousness. Unsettled. He wants to move.   | Mood symptoms and aberrant motor movements are frequent.  |
| You know, he wakes up. Even now if he takes a nap sometimes he gets up and he thinks it's the next day.  | Loss of circadian rhythms.  |
| ...he talks very easily and readily, even though sometimes what he says doesn't make sense   | The caregiver noted there was difficulty with language, the context; not speech, he was articulate.               |
| He is a bit afraid of being in the dark.   | Anxiety is recognized.  |
| And 95% of the time she goes off, starts screaming, "help me, get the police, he's trying to kill me."   | Severe delusions are described.   |
| ...sometimes [he] is very, very angry... sometimes   | Hyper-reactivity and agitation are identified.  |
| Her oldest daughter usually comes on Sunday morning at 8:30 which allows me to go to church. Last Sunday, I got back [and her daughter] was panicking, "mommy didn't know me."   | Cognitive impairment symptom of agnosia was recognized; family was confronted with unpredictable and labile mood. |
| So, it's difficult. It really is difficult. Some days, it's like, oh, why, you know, why and he gets angry and then he gets sad and then he gets depressed, and then he'll laugh...  | NPS symptoms of mood swings, hyper-reactivity, and labile depression and euphoria were recognized.                |
| And with the children talking about things about the grandchildren and now that isn't there. That isn't there. Oh, my son's oldest son was very ill— you know, we really couldn't talk about it with him because he just would take some of it in and then he'd forget it, you know? | Cognitive impairment symptoms of amnesia and executive loss were familiar.  |

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### Theme 2c. I See the Dementia: Knowing the Disease

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| Relevant Statements<br>Extracted from Original Protocols  | Formulated Meanings  |
|---|--|
| And I haven't quite gotten to the point in my life where I completely understand the [dementia] sickness and the symptoms.  | There is some knowledge of the dementia as a disease, but there is room to know more.        |
| And their [people with dementia] moments, and I don't know what percentage of the time these moments fail and when things are good— you know we laugh and giggle and did everything, it's fine and then, boom! It's just about that sudden and that abrupt and that unpleasant.                 | Recognition of a lack of knowledge about dementia and the unpredictable nature of the NPS.   |
| And lots of times it seems to change though...he will be real thoughtful and considerate and loving and then the other times it doesn't seem to be so. He can get loud and defiant. I figured its part of "it" [dementia disease]. He's never been like that, so it's just part of the disease. | Recognition that there is a labile nature of the NPS that can be attributed to the dementia. |

Yeah, yeah, but I love him. I tried very hard to find the positive. It's not always easy, right. But it's, kind of, pitiful to see how this, these diseases diminished him, you know? ...a very competent and capable person, now confused and like a child, you know, [he] might be a child again. Confused, just mildly impaired with his memory, you know, short-term memory. You ask him about his time in the service, his time as a child, then he's got it all. But you ask him what day of the week it is and it's not there, how old he is, he says he is 35. his world stopped.

He came towards me and grabbed me and I felt "whoa, I have got to really watch myself."

When we are out or at church, I do think he is a little more noticing of me and wanting to be really close, I mean not so much because we are husband and wife, but more like wanting to be sure we are not too alone and that he might really be frightened by it. I notice there is a little sense when he is not right here in our home, that he is sort of looking to be sure I'm not too far away. I am glad that I am there.

It's the apathy I think is probably the most difficult thing to deal with because he was always very engaged and we did a lot of stuff. And he's just not interested in a lot of things anymore, but we keep going, like, he used to golf in the men's league and he was a really avid golfer; now he will only golf with me. So, just, it's an evolution apparently.

I want to, kind of, get a handle and get my head around it [the dementia].

On the surface, it's tough the way everyone said it would be.

There is a part of me that's a little scared and especially when she was getting so tired, and so cranky, and so not sleeping and just feeling not herself.

Well, there are days when I don't feel like he's my husband. Then there are times when he becomes the sort of curse like I feel like I'm living with this other person. It's not really my husband. And he'll say things and do things that I know he would never have said or done. For instance, he never would have called me a bitch. It's very...in the beginning, I did feel a little hurt because I still felt where this is him saying this to me, but now I don't have that anymore.

Recognition of how the disease is complex occurs in stages and each symptom may have multiple domains.

Recognition that NPS and dementia behaviors may be provoked by a stimulus and that a strategy to respond is important.

Spouse recognized NPS and behaviors are site specific and that safety and reassurance is a therapeutic intervention.

Appropriate recognition of changes caused by the dementia and a comprehension that this disease is progressive in nature.

There is a desire to know more about dementia disease.

The participant identifies dementia disease as difficult by talking and learning from others.

Lack of knowledge of dementia symptoms contributes to decreased efficacy and overt fear of the unknown.

Recognition of the severe dementia effects on behavior, the spouse is taking a more objective look at dyadic interpersonal relationship and understanding how the disease alters intention and social boundaries.

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### Theme 3a. I Feel the Dementia: Loss and Hurt

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| Relevant Statements<br>Extracted from Original Protocols   | Formulated Meanings   |
|--|---|
| And so, the bond of being really close seems to be disappearing a little, – all the time.  | Recognition of closeness decreasing in a progressive way.   |
| It's easier for me, if we go [to a restaurant], just the two of us, or we go with family, her daughters or with kids or whatnot because she is less apt to go nutty. But not always, you know, the first time it happened, one of her grandsons, like, the poor kid was horrified, the look on his face. They don't understand. I mean, she just loses it, you know.                         | Literal loss of emotional regulation and figurative loss of the grandmother role.   |
| I feel really alone. Even with him in the room, I'm alone. It's almost like you are watching it. I'm watching my husband go away from me.  | Recognition of loss of personhood and the changes in the typical expected relationship of husband which are dramatic and observable.  |
| You know we laugh and giggle and did everything [that was supposed to be done], it's fine. And of course, you remember these things happen, did she remember? I don't think so.  | There is a loss of mutual shared activities in the construct of dementia's amnesia.   |
| After a while, you don't want to have to make them [decisions] anymore because you're making them alone. Your partner is gone—physically, they're there, but it's just the shell of the person that you remembered and then you want them to be... [the old partner], and that's very, very difficult sometimes.   | Notable loss of the executive ability, interdependence, and shared decision making, with a strong, longing desire to have them back but knowing you can't.  |
| But now I really have – I've really accepted a lot more; I've been able to get through it. I do really feel though the hardest thing is not having conversations with him and not being able to bond that way. I think he's not there sometimes. He's just not there.  | Loss of communication between husband and wife is difficult, not just talking but sharing. The loss is seen as an abstractness or invisibility.   |
| And then the other thing would be when we show each other the sign of peace, this on Sunday, we always do it first. We say peace be with you and we always kiss and this one Sunday he didn't, he just went to everybody else and everybody else just looked at me and I was just thought maybe he will get to it, but I mean it's being ignored I guess, and I am trying to get used to it. | Recognition that the spouse has lost her identity as 'wife' to her husband with dementia's amnesia, egocentricity and agnosia.  |
| But now there are so many times now that he isn't there. It's very difficult to accept that – I keep saying to myself, this is the disease. It is the disease. It is not [him]. And I think it's difficult sometimes to explain that especially to my children because they think that I'm still living with their dad. And many times, he's not [their dad].                                | The expectation of being a husband and father has altered in a diminutive way for the caregiver spouse, but children still assume the wholeness of "dad."   |
| I do think from the other side [there's] not quite the connection; ... certainly, a loss, but [it] certainly may not be obvious to him that there is that distance. It is a sense of his not really connecting; [There is] the vagueness on his part.  | The husband with dementia is not able to participate to the fullness in the marriage and he does not identify it as an impairment. The spouse describes remoteness and ambiguity from her spouse. |

I have that sense of loss that he is not all there.

Before her husband was complete; now there is a lack, missing parts, or partial absence of her spouse.

I feel like I'm living with this other person

A new identity for the spouse care recipient; an altered personhood.

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### Theme 3b. I Feel the Dementia: Sounds and Silence

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| Relevant Statements<br>Extracted from Original Protocols  | Formulated Meanings   |
|---|---|
| I take her out to lunch almost daily but our social life is different. And 95% of the time she goes off, starts screaming, help me, get the police, he's trying to kill me. You know, people look at you like you've got two heads.   | Dementia causes disruption of the speech and emotion center typified by amnesia and aphasia, but conversely the language may be loud and boisterous, in context as well as psychotic.   |
| I think he doesn't verbalize many things, and I am not sure if he quite notices the difference. He doesn't talk, so I don't know what it is like to be him anymore.   | Anomia, aphasia and psychomotor slowing provokes a cascade of speech pathology culminating in the loss of meaningful discussions usually prized in the marital dyad.  |
| I think it could be hard to say exactly how I feel, but I think I don't talk to him as much now because he can't understand me, he can't understand what I say, he makes me repeat three times. And so, I get to the point where I think why should I talk on simple things like common things a husband and wife would usually make that aren't necessary.   | Spouse caregivers adjust their verbal interactions for convenience and to decrease anxiety. Sometimes there is a juxtaposition of speaking for the sake of sound.   |
| Talking sometimes is difficult. There's nothing to say, you know. It's quiet. As long as, you know, you're not being cursed.  | Quiet can be acceptable when the alternative might be a tirade of expletives from an expressive NPS.  |
| And lots of times it seems to change though— he will be real thoughtful and considerate and loving and then the other times it doesn't seem to be so; he can get loud and defiant.  | Dementia loosens politically correct borders and social boundaries, so that behavioral and NPS are uttered without empathy or the ability to sense the caregiver spouse's displeasure.  |
| Just talking with him it's hard these days; definitely different from before. Because we use to talk and joke and share things and all, but now I tell myself don't say it unless it's important because he is only going to want to know what I said and by the time it's repeated three times it doesn't make sense to him.   | Dementia causes frontal and temporal injury that coordinate complex thought and understanding which allows meta-cognition. Inattentiveness and psychomotor slowing prohibits multitasking, the interpretation of abstract ideas and the ability to forecast consequences. |
| If I have to come in and sit down, and wanting to tell him about something that I am thinking about and like something happened to a neighbor or you know, he just can't positively turn his head to hear what I am saying. He really can't pull himself away, even sometimes watching the humming birds in there at the table, and I think to say something... is there anything I can say that can divert | Dementia causes psychomotor slowing and alters the level of consciousness in that there is an extreme difficulty switching tasks, so it appears that a care-recipient is focused, but may in reality is in a semi-hypnotic state. It is often                             |

his attention [back] to anything that I am saying? I am pretty-sure it is just how it is.

When I say it there's a lot of silence, it isn't, just because he doesn't talk. We look out the window when it is still light out and we watch the birds and I might make a comment about, oh we're up to three morning glories (flower buds) opening this morning, that's our conversation now; there is a silence because he will just have nothing to say, then I just have nothing more to say.

perceived as ignoring or disrespecting the spouse.

The silence between a dementia couple is equally distributed. The care-recipient likely has aphasia and apathy, and caregiver gets no reciprocity or positive reinforcement with the one-side conversation; it can be exhausting. The quiet may be satisfactory, merely tolerable, or painful.

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### Theme 3c. I Feel the Dementia: Cherished Moments

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#### Relevant Statements

Extracted from Original Protocols

#### Formulated Meanings

And then she will remember about the person, tell you everything about the time we did this, the time we did that, she will rattle right through it.

There are times when the fog of cognitive impairment lifts and there is a genuine connection.

We went to another couple's home here and the husband has a little dementia, not too much. But he still likes to be social. And then there is another husband who is fine, whose wife has terrible physical problems. So, the three men watch football and \_\_\_\_ [husband's name] had the best time. But he couldn't tell me later he had a good time, how was it, because he can't recall the game. He couldn't remember who was playing. But he sat there and just enjoyed being sitting in the row with the three of them, the entire game which he would never do if I had it on in the house.

There are times when the caregiver as an observer can see their spouse responding to others with joy or contentment and this is reassuring, and the spouse can sigh in relief feeling some respite.

And then he will be real thoughtful and considerate and loving...

There are rhythms of behavior, not always predictable, when dementia behaviors are mitigated and there is a RC connection again.

So, this is just a serious card that he gave me and thanked me for everything that I do. So, it was one of those moments for him to say, I know you do a lot for me and then he signed his own name, *first and last name*. So, every day I try not to hang on to too much. It's what it is, this is what we signed up for, we took a long time to marry, so I'm okay with this.

A celebratory event can still be on the radar for a care-recipient, but the traditional behavior, or the emotional expression, or level of expectation may be altered.

And it can be wonderful. I feel good when he'll ask me to go for a walk with him because I feel like we're together; when we do that because we always – in our marriage, you know, in our dating, we always took a lot of walks.

Reminiscence and re-creation of thoughtful times, behaviors and activities allow caregivers to recapture old feeling of warmth.

We were not a touchy-feely family. So, we're pretty much the same, but the intimacy at night is very important to both of us, it is! Yes, because he needs that [too]. So, that's where we do a lot of hand holding, yeah. So, that's a support for both of us, because that's our old selves.

Familiar rituals, like using muscle memory, allow a re-creation of traditional affectionate marriage behaviors (holding hands and marriage bed) that are reassuring to spouse caregivers and care-recipients.

He'll always say good morning to me, and put his hand on my shoulder as he's walking by. But I don't think that's any different than it has always been with us.

We took that trip on the ferry with the memory group. Well it was really wonderful, and I'm glad we did it. Because it was different and we both enjoyed seeing everything. At first I was a little skeptical but in the end, you really enjoyed it. We need more of that.

He looked at me sitting in our living room and looked right at me, and said, "it's just like when I'm with you at supper I don't have it in me anymore to make conversation." It's very unusual for him to say anything that intense, he very seldom addresses anything about how he is now or how to deal with one another, and he looked at me and said, "thank you so much for carrying the conversation" [at a family dinner]. So, he was saying that, and to me that felt very intimate and like he was really talking to me not just talking about what's on the television or... It was and it was like a gift and because it was sad but a kind of a gift.

When I come into the room and he is reading the paper or something, and I say something, he looks up and he knows it's me (sigh and smile)— that's good.

Expressive touch communicates regard and affection even when they become rote and habitual.

Alternative and new ways of incorporating mutual activities can be shared; a planned event is stimulating and distracting in a good way.

Intimacy takes different forms as dementia progresses and when there are moments when thinking and speech are clear and spot on, it reinforces the relationship closeness. Intimacy may take on a melancholy nature but is still seen as positive.

Agnosia that waxes and wanes is difficult for spouses.

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#### Theme 4a. I Respond to the Dementia: Advocacy

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##### Relevant Statements

##### Extracted from Original Protocols

##### Formulated Meanings

It's a lot like having children again, the planning that you have to do and organization, yes, absolutely. Yes, absolutely it is!

Parenting the person with dementia is a metaphor for the support and care required; it is the burden of care without the joy of launching independence and decisional capacity.

And he actually when he walks, he likes to walk by himself. And he does have a pattern of where he goes, but he's had two times when he's gone beyond and went down on the highway, and ended up somewhere. And some neighbor spotted him, we were going frantic trying to find him and we did find him. This was in the spring. We have our neighbors all alerted. Whenever they see him alone I get a call, so I make sure I'm always with him.

Dementia behaviors and lack of ability to identify consequences triggers the need for safety and surveillance; i.e.: to protect them from possible injury and contextually in that nurturance and affection will prompt a desire to be extra careful.

I want calm, peace. Right. I don't like to put him and myself in situations that I don't have a control over. So, I stay with him all the time. He'll say while walking around Target, he'll say he needs to go to the bathroom. I used to be able to let him go— he used to say I'll be right back. Now, I go with him because he would walk around the store looking for me because he couldn't remember where I said I would be, ... and then it's stress for me, looking for him and stress for him because he can't find me.

The spouse desires extra control because it prevents injury, embarrassment and catastrophes.

Well when he feels badly I can tell, and that's because he needs something.

Dementia's symptomatology makes the care-recipient a poor communicator, thus

You want to protect them. You don't want them to get into a situation that will make them unhappy or hurt.

[It's] almost like reading his mind or connecting the dots; I don't know the insight you have to explain what he's trying to say or do. And also in his agitation I sense when it's there. And that's when I just have to be very observant and close.

Yeah, we still go out with people, and now more and more people are being told by me what the problem is because in the beginning I felt like he just would sit there and be pathetic. And like not having interest in what someone was talking about and I didn't want them to think that he just was like, "I don't give a shit. I'm just here with you but I don't really want to be here." But that's not at all what was happening so I told people more and more that what the problem is, and they understand.

We would like to drive, get in the car and, you know, go north, go east, go west, go south, just you know, for a short three or four days, that kind of things. I find now that gets very confusing for him. I have to do the driving first of all. I don't let him drive anymore, although he still has his keys and he still has license. It's like swallowing my, you know, my throat if I take my car and his car is still on the garage. I wonder the whole time I'm away- is he out in the car?

And it's challenging, we went on a long walk and she said, I'll wait here for you and I don't know whether I should wait with her, or continue on my own. Will she be OK on her own? I think about that now.

We do have a problem with (*whisper*) incontinence. This is around about the time we have to check (to make sure he's gone to the toilet). And especially if he's going to go out and... the people he goes with, well they don't want him going [urinating] on the car seat.

Yes, you don't want them to get themselves into situations that could be dangerous or could be embarrassing. You know, I think walking through the supermarket and I see him take a candy bar while waiting in line and put it in his pocket. You know, and I'm thinking, so I try and call him out about it quietly, you know, we have to pay for that. He said, oh no, this is mine. I wouldn't want him to be embarrassed by somebody stopping us and say, you

the caregiver becomes an interpreter and translator.

A protective and defensive strategy prevents the care-recipient from being in a situation that may be uncertain, with the full knowledge that persons with dementia will always possess feelings and desire for self-respect and dignity.

Caregivers use all of their senses and knowledge of the individual biography of their spouse to make leaps for communication and intent. There is a pervasive need to be close, watchful and offensive in strategies.

The spouse caregiver expresses for the spouse, his desires through interpretation, and alerts others in a respectful way to explain dementia behaviors.

Cognitive impairment and dementia mood symptoms make driving a high-risk activity. The caregiver recognizes the danger. The notion of "taking someone's keys away" has societal implications of: incapacity, failure and powerlessness-loss of control.

Caregivers find it difficult to identify potential risks of danger because dementia symptoms are unpredictable. It is a fine line to protect vs. allowing autonomy.

Incontinence when related to dementia, not physiologic, denotes cognitive decline as a functional loss - it is compared to childlike care needs. Caregivers desire to preserve dignity and prevent embarrassment due to possible bladder accidents.

Spouse caregiver is protective of her husband and wants to eliminate the possibility of them as a couple being in a socially unacceptable situation that might be construed as embarrassing, criminal or thoughtless; scrutiny of a



know, put the candy bar back, or whatever; it's as much for me as for him.

When you start taking care of someone, it is primary. It's like taking care of a toddler. I mean, you're doing everything for them. Yeah, I bathe her, feed her, dress her, and undress her.

dementia spouse's behaviors takes on a greater and more significant role.

Spouse caregivers assume the role of direct care provider for custodial ADL because their spouse is unable to perform those duties; they desire the care-recipient to be clean and presentable in public. It is an essential role for this spouse.

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#### Theme 4b. I Respond to the Dementia: Compassionate Love

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##### Relevant Statements

Extracted from Original Protocols

##### Formulated Meanings

He doesn't – well, I mean that's all he wants to do is be next to me, you know, I'll take him to a movie. He doesn't have the foggiest idea what's going on, but he wants to be there.

Spouse recognizes and capitalizes on nearness as an expression of safety even during events that are beyond the understanding of the care-recipient. The connection (identity recognition and safety/reassurance related to proximity) between spouses persists.

I tell him very often I love you. Yes, I love you, and then his eyes light up. It's a good feeling he gets. And even when I'm angry I say, "You know I love you John\*." And I just want to make sure things... you're safe.

\* *pseudonym*

Love supersedes reality of disease and anger related to safety (much like hugging a child who darts into traffic).

I feel very... almost privileged in a way to be the one that can be helping him and I call that closeness.

The marriage bond and vows surpasses interdependence with a higher-level love than that which we equate with "affection."

She will come down and we will always kiss even before breakfast or whatever; and a lot of times if we're watching television, holding hands, that sort of thing. – and we still sleep together. We sleep in the same bed. So, I mean there is some connection that remains to this day. And sometimes it works if I call her honey or something like that. I mean that's good for her, yeah.

The caregiver identifies daily positive physical aspects of a nurturing close relationship which is perceived as a "connection" by him and something that is "good" for his wife, the care-recipient.

But I think we both kind of have old souls too. You know, so we kind of can live with things. Yeah, with compromise we don't expect life to be perfect. It never has been and never will. [We were close], I [still] am now, —very! Closer than I've ever been actually. I just feel so much compassion for him. There's a lot of hugging and a fair amount of joking.

The caregiver recognizes changes with her relationship, but their history together was one of concessions and adaptability. The dementia disease is another chapter which requires flexibility and accommodation. RC has expanded with compassion, humor, and hugging (encircling with arms was first used in 16<sup>th</sup> century, an Old Norse word *hugga*, which meant to comfort).

If you can get her a table, when you are sitting here, you have a lot more control, it's easier for me to feed her so you don't cause a spectacle, you know.

There are deep social constructs to meals and the act of "feeding." Nutrition, pleasure of eating and mutual shared

Because he can say something, and I'll say oh my God! When he was describing a house shrinking and being inside another of our houses. I said, God it must be so awful to be so confused. And he said, yeah. I mean he's never been one to talk, he's an engineer. Feelings don't exist, but yeah, he does describe how he's feeling. Not in great detail but, and then I just feel so sad, I can't imagine.

We [used to] talk about our love, and talked about our closeness and talked about our blessing and kept talking about it and I guess now we are just... we're living it.

I will say, you know, many times even when he's upset, I'll say, you know what, I'm here for you and I love you. And sometimes it calms him a little bit.

And the loss is with your, ...all kinds of intimacy. Sometimes I will just crawl into bed and just cuddle and it's me pretty much doing it, he doesn't respond, and I am just talking about cuddling.

Yeah. I mean that we have to change. You have to realize and understand. They're not the way they were. He understands and sometimes he is upset because you baby him, he can't, he can't [do for himself] ... (*tearful*)... because he wants his dignity. And so, you have to realize that...you have to realize that! So, that's how we proceed.

So, there are times when I think, oh he's just doing that to bug me or he's just not paying attention when he says "why," every time I say something; and I get like, come on. But then I realize, I step back and I say, okay well this is the dear man. We've been married for almost 50 years and we had a wonderful relationship up until this. So, I have to get over myself, feelings of being frustrated to go no further now, to be more loving.

[We've become] more like friends; the love had been a lot more unconditional. All of our closeness and physicality, and kissing

socialized activity are mediators of a relationship.  
(Compensatory strategies families use to overcome eating conduct changes or their perception of the mealtime experience have not been well investigated.)

Sadness and melancholy are emotions described within the relationship. The caregiver verbalized an ambiguous grief sensation in the ah-ha moment— a deeper connection because of her husband's visual description of what the NPS feels like for him.

The RC surpasses the dynamics of communication toward the manifestation of now living the relationship. "Living the doctrine" is a high-level commitment, and based on vows or pledge earnestly taken.

"I'm here for you" in today's jargon means: I've got you, or I've got your back. It encompasses a broad lexicon related to reciprocity, overarching care of all needs including finance and safety, or just being in the moment with mindfulness and no prerequisites. Like love, it is an open positive concept.

The caregiver describes a physical affection, expressive touch, it is one-sided, but satisfies a need the spouse has and continues to desire.

Interpretation of what a care-recipient is saying, attempting to say, or may be feeling is a critical element illustrating the care connection from the caregiver's stance. This caregiver, "knowing" her husband, frames the way forward is based on "the way he used to be and what he used to say and do."

Cognitive behavior therapy and problem solving principles are intuitively applied with the result redirecting the caregiver back to elemental love. She remembers and so recommits to the love relationship.

The adjective unconditional means I will continue to love, under any

before you leave every time, and when you come home every time, and just various times during the day, you know, and we just look at each other and say, "it's time!" and have a big hug.

circumstance, and no matter what happens. The caregiver identifies the progression of the disease, a timeline of potentially changing events and the commitment which means an altered lover-to-friends concept.

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#### Theme 4c. I Respond to the Dementia: Imperfect Caregiving

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##### Relevant Statements

##### Extracted from Original Protocols

##### Formulated Meanings

Many little things like reminding her before she comes to bed, could you please turn off the lights and they don't get turned off. Little reminders for her that the dish by the sink is, has pills in it and then, and I'd put them there carefully in the correct amounts and could she please take them and then, the next morning, I get up and the dish is full and I was unsuccessful. Some of the pills are important, so they almost have to be handed to her individually with a glass of water.

Dementia disease requires a flexible caregiving approach to produce efficacy. The caregiver recognizes some new strategies and identifies the important things, but is still in a learning curve.

With the disease, there is a lot of repetition of decisions, like, what are we going to have for dinner. I am still adapting to it. I've adapted to having to do it, but I haven't adapted as much as I want to due to frustration.

The scale of dependency alters in dementia and the caregiver assumes a greater burden. The caregiver identifies an essential need to change in increments, motivation and mood.

Some days it's a success, other days it's just oh God, I'm so glad he went to sleep. So, and some days I don't even want to have to deal with him because he's confused and he's agitated, and it's just some days it's just too much.

The caregiver recognizes all days are not the same; some seem spot-on but others are a relief to get over. There is a desire to escape when dementia behaviors are raging, know that the caregiver perceives they are not ready or able to always be there 24/7.

Right now, it's getting aggravating because she doesn't do anything anymore and I get to do everything and get no credit for it.

The home is out of balance because of the care-recipients function and cognitive losses, and that persons with dementia are no longer able to empathize (the capacity to understand or feel what another person is experiencing from an external context) because of the frontal temporal damage of dementia disease.

The caregiver recognizes the change in reciprocity change but has not embraced the knowledge that those exchanges that used to be, are no longer possible.

"Walk with me," he said. So, we look like a couple that have just had a spat, because he is way behind me and he's got further and further behind, ... and I just want to keep moving.

The spouse illustrates a metaphor for a desire to escape the demands, responsibilities, lifestyle and future, expected as a caregiver, and necessitated by dementia disease.

Well now our relationship, it's kind of difficult. I feel sometimes, well, I feel really close and then not so, because sometimes I get angry... at a lot of things that happens

And the staring off into space, which ... then, I would just get cross at him. Why aren't you paying attention? And now of course I could kick myself. I worry that I'm not a good enough caretaker. That's it.

So, in a way he's thinking, his mind is working, but he doesn't seem to say that—no- he doesn't say, "oh I don't want to go, I'm scared. I'd rather not go in case I see X, Y, Z", you know? I don't know what to do.

There are no same days. But, oh yeah, put what happened yesterday behind! ... I have to make sure to do that because it's too much. If I don't.... I always try to open and pull out that little statement that says that: *He's not giving you a hard time, he is having a hard time.*

I'm sure I'm not unique in this (caregiver role) but I'm, ...given what I've gone through (recent surgery) and as it relates to my memory and my health, I'm less than whole too.

Our relationship... it's nowhere near as good as I think it ought to be. I hear things when I go to the support meetings. And the relationships they describe, I don't think we have [that]. And maybe it's because we never had that relationship or haven't had that relationship for 35, 40 years. We have a friendship relationship and a living together relationship, a deeper binding loving relationship.... it doesn't seem to be there.

I have to keep the frustration, you know, not only keep the frustration out of my voice, but keep it out of myself. I don't need to be frustrated by that, it just is. But it doesn't help anyway.

At night, I blowup and he stays calm. Isn't that the opposite? Well, because he takes a long time to go to bed and I want to get in bed and have the lights and the pills taken and the eye drops finished and it can take forever. And then he looks at me and he sort of begins to

The spouse caregiver recognizes RC feelings expressed as anger, are related to and in response to dementia's functional losses, symptoms and behaviors. The dementia is provocative and alters the relationship in a recurrent way.

Dementia disease and its symptoms and the caregiver's response are recognized and evaluated with new knowledge. Even in an established learning curve, the future of more dementia symptoms causes the caregiver to fear her ability to be effective based on past blunders.

The caregiving is saying her husband's aphasia and inability to discuss things in a meaningful way are challenging; she realizes she cannot always interpret correctly and may make mistakes.

The caregiver recognizes some unsuccessful interactions and a tabula rasa strategy employed. The spouse has transferred the responsibility for dynamics to herself and that the care-recipient should be given a pass due to the dementia.

The spouse realizes he is not as healthy as he would like, and that may interfere with his ability to care in an effective manner. He uses "less than whole" eloquently to describe his physical health issues and his wife's dementia.

The husband caregiver measures his RC with others and finds he has a different type of marriage than the traditional. He has not realized that there are others too who have an alternative relationship, then the typical 20<sup>th</sup> century stereotypical happy Hollywood-movie-marriage-tradition.

Frustration, impatience and reactivity thru verbal and non-verbal communication is a challenge. The caregiver recognizes her response affects the caregiving outcome.

The spouse caregiver can become impatient in word and deed, but recognizes it, names it and compensates for it.

laugh and then I'm done with it, I'm ridiculous (*laughter!*). That's right. He never refers to it. I call it loud impatience... (*laughter!*).

So, all these little wee things that fall on me, there are some days that it would help me [if I could] unload... to harp on him about something, then it's like o boy, I just think not now. I know we're all doing the best we can, him too. But absolutely there are things that every now and again, I think it crosses his mind that I'm doing a lot of household everyday stuff and he'll sort of back off. But for some days, I think, he doesn't really grasp that I'm trying to work and grocery shop and do reports and get the paper and make sure that the rent is paid, the utilities and make sure all these things are going on and then in the middle of it all of a sudden, he'll say, "did you look into whether I can get that Velocity TV channel yet?" No; not yet (*sigh and eye roll*).

The spouse caregiver recognizes many of the critical elements of caregiving burden and how difficult it is to accomplish it in light of a spouse with dementia. It is human nature to be reactive, to respond to buttons pushed, and answer inopportune comments impatiently. The caregiver has distilled the symptoms and behaviors of dementia and how the locus of control has shifted to her—the caregiver.

#### Theme 4d. I Respond to the Dementia: Balancing the Scales

| Relevant Statements<br>Extracted from Original Protocols   | Formulated Meanings   |
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| And I thought it would be better last time if we stayed at a motel but at two o'clock in the morning I got a call from the front desk, he's wandering. I took a trip to San Francisco and it has been the first time since his dementia that I haven't taken him [with me]. I can't do it anymore.   | The spouse caregiver changes the usual sightseeing travel due to the safety problems of her husband's wandering especially in a strange city. She is sad to end the shared activity, pines for the old days, and yet identifies her own need to maintain travel.  |
| I mean he doesn't seem to do anything now. He doesn't seem to want to read or go for a walk or go to yoga class where I say let's go it's nice she's kind, she's gentle we can try it. And no, he says no to a lot of things now and before I feel like he would try it even though he was nervous about it but if I kept after him he would try it. So, I go.   | The caregiver spouse persists in trying to induce her husband to try activities; dementia has profound effects: apathy, egocentricity and an extreme need for safety and familiarity. The spouse attempts to maintain shared activities, but will attend on her own. There is a desire for respite, and not participating in solo activities reinforces the caregiver's hostage in the home feelings. |
| So, I go out a little bit every day and I just keep doing what's good for my mental health. I do some yoga, I play tennis when I can and play some golf.   | The spouse caregiver recognizes a dual life and that she maintains good psychological health to continue caregiving in a therapeutic way.   |
| Right now, this is my world, and whatever I have to do to make things be smooth and calm and for me to keep my sanity, that's what I do.   | The spouse caregiver maneuvers and acclimates to the change with a goal of peace. She thrives on control and the status quo in her dementia world.  |
| I've given up when I do laundry... I have a pair of underwear for everyday of the week and he has one [too]. You know what?... unless he pooped himself or fell in a puddle, I'm not going to go crazy over something like that. Nobody ever died from wearing the same underwear twice in a row. So, I learned a little lot of things aren't important to go and try to tackle them. He sleeps later than I | The caregiver has managed to control her environment and altered her expectations in the desire to keep it calm and therapeutic. Flexibility and knowing the difference between battles and who wins the war is key.  |

do, because he takes Seroquel at night, so it gives him a good solid sleep, so I get up at 5:30 or 6:00. He doesn't get up till around 8:30 or 9:00. So, if I need to snatch some clothes or do things do laundry, that's when I do it.

I don't want him to feel that he's getting sent there (Adult Day Services) and he doesn't fit in. I need him to have somebody to talk to and interact with. I don't want him just sitting in a chair and listening to the music because that's not going to help him mentally. And then, the other part of me says what do you care, just send him, you'll get a break. Okay. So, there's the juggling again.

I am thinking too, that maybe I am having someone come in, it might be good for him to just have a change, maybe a man to talk to or something instead of me being here all the time because 24/7 is not easy, probably sick of me. When he is lucid so to speak, I think the conversation would be more on a man's terms than talking about [female or wife's] things.

I don't add anything to complicate my life right now. It's just too hard. For my own benefit, I need things to stay status quo.

To me, the caregiving meeting is very helpful. I feel when I hear someone else talk about their problems or the challenge, and I think that, that happens with us too. So, to hear different people who are going through this, to me it's helpful. Now and then, I'll call another support group member and we talk and she tell me how I had helped her and she has helped me, one on one, ...one on one.

Simple things, simple things! Like I said, sometimes it's like living with a stranger or living with two different people. One is the husband I know, and one is not. Sometimes, he mostly sleeps in the spare room... once in a while, you know [he'll] sleep in our bedroom, and I just let [it be], whenever it happens happen, wherever he wants to be, he's comfortable, that's fine, that's fine.

You know, you look at this person and you try and remember, why did I fall in love with you, or you know the quality of your life stinks, you know why? Why did this have to happen to us? We didn't deserve it. You know, we've worked hard and you go through all those emotions, you know, and you just got to figure there's a reason somehow, and you just do the best you can because at the end of the day, you get into bed and you just say, I did what I needed to do to make his day good and mine as good as it could be, so. And as I said to you, this is the box we live in now.

I'm lucky in many ways because he's getting his care thru the VA and because he's service connected. They're a big help. I can call and if he needed someone to help him with his – helping with his home health, they would send someone to help him shower.

Decision making can be a challenge and this caregiver struggles with respite vs. meaningful day care. She wishes the best but may settle for something less. The juggling image illustrates the active energy and work to balance each spouse's needs.

The introduction of outside help to help with the home and care-recipient is a milestone in the dementia caregiving journey. The spouse caregiver is addressing her husband's needs that she can't provide.

Dementia caregiving is very demanding and caregivers pick and choose what action is acceptable and what is dismissed or temporarily left behind.

Spouse caregiver uses a support group to learn about the disease, strategies and is able to unload. Talking in a meaningful-catharsis, with others who have traveled the dementia path contribute to harmony.

The caregiver's expectations are flexible and allow room for the care-recipient to decide where to sleep, emphasizing her desire for him to be happy and content. She is willing to "move the furniture" if there is an acceptable outcome.

The caregiver describes a fragile existence but within a stiff cardboard box– a protective covering. She recognizes the unfairness and a tipped scale; at the same time chooses to give more to her care-recipient husband and willingly accepts less for herself.

The caregiving demands are too much for this spouse, so she can incorporate an external solution to buoy the care needs of her husband.

I've been a part of the church all my life and I prayed for my faith to stay strong and I pray every day and I am part of a prayer group. It's not; it is not a stop gap measure to you know like a glass of wine or something, it is just so much a part of me and I think that it has helped a lot in dealing with loss.

It (dementia disease) always, lies to some extent like other people's dementia, but then its just another something new... new moods... new issues... new ways of looking at things. You know? And I think I've gotten pretty good at changing the way I look at things... to be consistent within this new batch of behaviors... and the 'new version' of Mary\*.

*\*pseudonym*

I do have a faith. I sit quietly, since we've had good weather, I sit outside and I actually talk to God. I'm thankful for my husband. You can always find something to be thankful for. I do have a faith. I have been very thankful and asked for strength many times. I've been thankful many times because I have it, I have that strength.

So, you know I – like for instance if I go on a bike ride or something like that, I will just go for a bike ride while she is napping, or sometimes I will hire somebody (home health aide) for me to go to Block Island or something like that; and I can spend a day.

Spiritually. It's very much a part of mine [my life]. He is not a person that prays, but we just – we went to mass today at 12:05 because he asks to do that sometimes. But we don't talk about prayer a lot. We don't pray together. To me prayer is very personal...he knows that I pray at night...for meditation, just being in the presence is all you really need. Yeah, so I could work with that [if I couldn't go to mass], I could.

Church is helping me get through this. I'm a cradle to grave Catholic.

I want to mention is the role of our family dog, Duffy, a 5 1/2-year-old Labradoodle. He is probably the key person (K-9) in taking care of [my wife]. He [the dog] can instantly diffuse a potentially ugly situation and be the best companion for the patient and the caregiver. I think this is something that may be underplayed in the treatment and management of a household dealing with this horrific illness.

It takes a village for this disease. It takes more than one person, people and things, and money and time. It really does. I myself have said this same thing, I just think I knew what all this service was all about. But until you're living in it, you really don't know.

The caregiver finds spiritual consolation strengthens her ability to care physically and emotionally.

The caregiver is able to integrate and accept the changing persona of his wife to keep both of their lives in balance.

Spirituality frames the caregiver's existence and ability. Having faith allows her to be thankful for her spouse with dementia and as well as allows tensile strength. She has a religious pillar on which she can depend and find comfort, and perhaps 'life' answers.

There is an acceptance of others providing care to benefit the caregiver's health and wellness.

Religion and spiritually mindful activities that allow a caregiver to be alone and inclusive of care-recipient. It can be accomplished anywhere.

Catholicism is an external support that allows the caregiver to be the best he can be.

Pets are increasingly part of the family and marital dyads. They can provide a calming influence, allow expressive touch via petting and holding, and are therapeutic as *someone* to talk to and an incentive to walk.

Spouse dementia caregiving subsumes many roles of spouse, husband or wife. The burden is incredible. This caregiver recognizes it can't be done alone; she learned that on the dementia journey.

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### Theme 5: A Future Together

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#### Relevant Statements

Extracted from Original Protocols

#### Formulated Meanings

I've got a view of what it (dementia disease) might become like, but we wrote our own vows, and nobody that I tell this is surprised knowing me that my vows were basically a commentary on the traditional vows. And the key part, a part of that germane to this conversation is that, I started off by saying that I, John\*, the person you see before you, without pretense or disguising, take you Mary\*\* (spouse with dementia), that's not the Mary\*\* of my imagination or my wishing, but the real – Mary\*\* that you are, and whatever Mary\*\* you might become. So, whatever Mary\*\* might become, that's what I took. It's what I signed up for.

\*John and \*\*Mary are pseudonyms

Talking about, maybe going into care... So, I try very hard to not to be so blunt about when one of us may have to go into long-term care, where do we need to be, to do those kind of things, I don't know, I really just wanted say, when **you** go into a nursing home right, right; ...kind of blurring the edges a little bit and take down some of the sharpness, because he is well enough aware of what's going on without me poking him in the eye about it. You know?

I think what proves our closeness, is... I don't want to see him go over to the memory unit or nursing home; which I thought would be easy at some time. Well right now I don't want him to go. Yes, I mean the time may come in.... if I can't physically take care of him, then you have to do something.

I really love home and house work, I'm not great at it, but keeping house, spring cleaning, home life— it's really big to me and yeah if I am lucky enough to be blessed, you know with a husband, and if that needs taking care of... that man now and later, that's kind of how I'm made. I am not very modern I don't think.

And so, knowing that I have the expectation that no matter how little of her mental capacity and her language skills or whatever might be there, I know "she" will always be there. So, that's making it possible to sort of face what's coming and know that the closeness will still be there.

I don't know what to expect. I don't know what the future is.

It's made me make decisions on my – on our future together. You know, I have no qualms about when it's time to put the house on the market and move into, you know, independent living facility or just an apartment, less stress for me.

I'm 65. There's no saying that I'm not going to start to be forgetful too. So, I try and make sure that I'm – that if something ever happened to me, somebody would be able to come in and see that

Unconditional love is the scaffolding this caregiver will use as the journey of dementia poses the unknown.

There are future decisions caregivers must contemplate, one of the most common is institutionalization. The caregiver tempers the choice of future living in the scope of both potentially needing help in the future.

Decisions for future custodial care often are parsed by burden: custodial care for incontinence and unremitting neuropsychiatric behaviors.

Caregivers are dedicated to providing care now and in the future.

The spouse caregiver remembers who she the care-recipient was and makes the leap that she will still be there in some way in the future that will remain as familiar.

The not knowing about how dementia will express itself as times goes on, is unsettling.

There is a pragmatic approach for some caregivers, who grasp the need for this disease that is unpredictable, need for help, and simplification gives you more control.

There is a high risk for dementia caregivers to also suffer from cognitive impairment. The spouse caregiver has



this is what this family needs and this is what – these are his needs. I make sure that I have medical histories and everything close, that again if somebody came in they'd be able to know that he's had, you know, he's spinal fusion and he's got metal plates and he's got PTSD and he has dementia. And you know, try and be as organized as you can be. You do. It's like running a small business

You have to have that mindset that this is not... this doesn't define who I am. It's what we have to deal with right now and we'll deal with it.

I mean I know it's going to be hard, and I'm very, very clear on where this [dementia disease] is headed and try to be mindful in this relationship to make sure we have our advanced care planning done, and our wills done and all this stuff in place and make sure he's made those statements; and this is what I want down the road and this is what I don't want. So, it's clear to me than anybody else who and what's to come.

And I told our son, I said, "You know the time may be coming that we should have someone full time, full time."

You know I just want to get through it feeling like I loved him. If a feeling of friendship is better than nothing..., but I can't connect with that anymore. You know, but I mean, it's still the commitment is there, and I don't feel like it's a ..., I don't feel like it's a duty I have to do. You know one day I may not be able to, and I do have friends that are like encouraging me now to start looking around [for a nursing home].

The past is very present a lot of times. the present sometimes. The future, forget it! I say the future is we both go. We have my sister who is buried here, and we have one grave stone, I'm sure her name is on it and so is mine, and we're all going to in the same spot.

So, we get, you know, we keep going. I think that's what you have to do, you have to keep going, like a journey yeah, and that's part of who I am, and I'm a person who just keeps going anyway.

Part of me wants to know what's ahead and part of me doesn't. The thought of having to clean him up if he has accidents..., when he has accidents, [it] just breaks my heart. Plus, I just don't look forward to it.

identified a safety plan for both if future health issues arise.

Being in the moment for care.

Advanced directives are based on the couple's desires and must include the healthy unimpaired spouse. This caregiver recognizes the prognosis of dementia and has an understanding of the desires of her husband with dementia, including the thoughts he had when he was unimpaired. Future plans give a feeling of peace.

Dementia planning may be measured by the amount of help needed; it is based on the care-recipients needs now and the future.

Despite the challenges of dementia, the unpleasant choices of custodial care, caregivers yearn to continue a compassionate love relationship in a variety of forms different from the traditional marriage concept.

The timeline for couples dealing with dementia is very much based on past, with reminiscence and preserved long term memory.

'Keep on, keeping on' is a mantra for spouse caregivers who recognize they have miles to go.

There is a fear of the unknown future as well as a desire to keep it hidden- because it might be too frightening; but yet there is awareness of the disease progression.

## Appendix K Empiric Variations of Fundamental Description

| Essential Constituent: 2. I See the Dementia |   |   |  |
|--|---|---|--|
| Subtheme                                     | Significant Statements  | Formulated Meanings   |  |
| Knowing the disease                          | And I haven't quite gotten to the point in my life where I completely understand the [dementia] sickness and the symptoms.  | There is some knowledge of the dementia as a disease, but there is room to know more.   | Variation: Understanding it                      |
|  | There is a part of me that's a little scared and especially when she was getting so tired, and so cranky, and so not sleeping and just feeling not herself.   | Lack of knowledge of dementia symptoms contributes to decreased efficacy and overt fear of the unknown.   |  |
|  | I want to, kind of, get a handle and get my head around it [the dementia].  | There is a desire to know more about dementia disease.  |  |
|  | And their [people with dementia] moments, and I don't know what percentage of the time these moments fail and when things are good—you know we laugh and giggle and did everything, it's fine and then, boom! It's just about that sudden and that abrupt and that unpleasant.                  | Recognition of a lack of knowledge about dementia and the unpredictable nature of the NPS.  | Variation: Identifying its unpredictability      |
|  | And lots of times it seems to change though...he will be real thoughtful and considerate and loving and then the other times it doesn't seem to be so. He can get loud and defiant. I figured its part of "it" [dementia disease]. He's never been like that, so it's just part of the disease. | Recognition that there is a labile nature of the NPS that can be attributed to the dementia.  |  |
|  | On the surface, it's tough the way everyone said it would be.   | The participant identifies dementia disease as difficult by talking and learning from others.   | Variation: Maybe I do not want to understand it. |
|  | Part of me wants to know what's ahead and part of me doesn't. The thought of having to clean him up if he has accidents..., when he has accidents, [it] just breaks my heart. Plus, I just don't look forward to it.  | There is a fear of the unknown future as well as a desire to keep it hidden—because it might be too frightening; but yet there is awareness of the disease progression. |  |

| Essential Constituent: 3. I Feel the Dementia |  |  |                              |
|---|--|--|------------------------------|
| Subtheme                                      | Significant Statements   | Formulated Meanings  |                              |
| Cherished moments                             | And then he will be real thoughtful and considerate and loving...  | There are rhythms of behavior, not always predictable, when dementia behaviors are mitigated and there is an RC connection again.                                      | Variation: Tenderness        |
|   | If I look like I my back is hurting, my husband comes over and pats me on the head. You know the right thing to do but still... I still have that.   | An affectionate expressive touch, slightly remote but not devoid of feelings from the care-recipient.  |                              |
|   | He'll always say good morning to me, and put his hand on my shoulder as he's walking by. But I don't think that's any different than it has always been with us.   | Expressive touch communicates regard and affection even when they become rote and habitual.  |                              |
|   | And it can be wonderful. I feel good when he'll ask me to go for a walk with him because I feel like we're together; when we do that because we always – in our marriage, you know, in our dating, we always took a lot of walks.  | Reminiscence and re-creation of thoughtful times, behaviors and activities allow caregivers to recapture old feeling of warmth.  | Variation: Mutual activities |
|   | We took that trip on the ferry with the memory group. Well it was really wonderful, and I'm glad we did it. Because it was different and we both enjoyed seeing everything. At first I was a little skeptical but in the end, you really enjoyed it. We need more of that. | Alternative and new ways of incorporating mutual activities can be shared; a planned event is stimulating and distracting in a good way.                               |                              |
|   | And then she will remember about the person, tell you everything about the time we did this, the time we did that, she will rattle right through it.   | There are times when the fog of cognitive impairment lifts and there is a genuine connection.  | Variation: Their old self    |
|   | And sometimes, he comes up with something funny and I'll think where did that come from.   | Humor may be an innate part of the personality and remains active thru all stages of dementia.   |                              |
|   | He still wants his sweets. He's always loved his sweets, that hasn't changed. Pie, pumpkin pie, pumpkin pie, he'll sit down and eat almost the whole pumpkin pie. I'll save the rest. He just loves his pumpkin pie, always did.   | Likes and dislikes are based on personality which endure thru dementia. The caregiver shares in contentment which is likely visible to her husband and reflected back. |                              |
|   | When I come into the room and he is reading the paper or something, and I say something, he looks up and he knows it's me (sigh and smile)— that's good.   | Agnosia that waxes and wanes is difficult for spouses; but when there is clarity— it is a magic moment.  |                              |

| Essential Constituent: 4. I Respond to the Dementia |  |  |                                 |
|---|--|--|---------------------------------|
| Subtheme  | Significant Statements   | Formulated Meanings  |                                 |
| Advocacy  | When I'm not there. I still worry about him taking the car, I have to be honest with you, I'll go to the gym in the morning and I'll take my car and the first thing I do when I open the garage door is I look to see if the car is there. I'm living with that fear, you know. | High risk behaviors are frightening for caregivers and are usually complicated by retained procedural memory (like driving). The caregiver recognizes a danger, but has not progressed yet to restrictions.  | Variation: Surveillance         |
|   | And it's challenging, we went on a long walk and she said, I'll wait here for you and I don't know whether I should wait with her, or continue on my own. Will she be OK on her own? I think about that now.   | Caregivers find it difficult to identify potential risks of danger because dementia symptoms are unpredictable—they wax and wane. It is a fine line to protect vs. allowing autonomy.  |                                 |
|   | He's been making a lot of mistakes driving, and I don't usually drive. I am looking at the highway signs and the speed limits and everything and making sure he is doing it right. It's exhausting.  | The caregiver expends enormous energy in the observation and scrutiny of activities which the care-recipients are still somewhat capable of doing but with a hint of danger.   |                                 |
|   | I don't leave him alone.   | A concept and judgment by caregivers which historically is a red flag! To leave them alone brings anxiety of the unknown to the caregiver.   |                                 |
|   | At this point I can still leave him alone  | A concept and judgment by caregivers which historically is a red flag! To not leave them alone brings anxiety of being hostage in the home to the caregiver.   |                                 |
|   | It's a lot like having children again, the planning that you have to do and organization, yes, absolutely. Yes, absolutely it is!  | Parenting the person with dementia is a metaphor for the support and care required; it is the burden of care without the joy of launching independence and decisional capacity with a maturing child.  | Variation: Parenting the spouse |
|   | When you start taking care of someone, it is primary. It's like taking care of a toddler. I mean, you're doing everything for them. Yeah, I bathe her, feed her, dress her, and undress her.   | Spouse caregivers assume the role of direct care provider for custodial ADL because their spouse is unable to perform those duties; they desire the care-recipient to be clean and presentable in public. It is an essential role for this spouse. |                                 |
|   | But it is on some days like having a little kid, you know, you can't wear that, you know, he's got shorts on and it's 30 degrees outside.  | Simple rules of living are difficult in dementia because of poor sensory perception, forgetfulness, and lack of problem solving. The caregiver must attend to the most routine of actions.   |                                 |

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|  |   |   |                           |
|  | I find that the meals aren't as social as they were. There are times when he will get up with his plate, rinse his plate up and set it aside to go in the dishwasher and he doesn't really sit with me. He is up and down like a child, sometimes you know when a child will get up and down.   | The caregiver describes that the social mealtime is no longer possible and her husband has the inattention of a child   |                           |
|  | You want to protect them. You don't want them to get into a situation that will make them unhappy or hurt.  | A protective and defensive strategy prevents the care-recipient from being in a situation that may be uncertain, with the full knowledge that persons with dementia will always possess feelings and desire for self-respect and dignity. | Variation: Shielding      |
|  | We went to the Veterans coffee shop on Tuesday and that was a success for me because there was – we were sitting at a table and there was a gentleman there who started to talk to us, and they started to talk about being in the service. So, I just excused myself and let him be. I knew he was safe. I knew he couldn't wander away and I just out into the hallway and kind of made myself scarce until it was time to leave.   | Support services must earn the trust of caregivers, because they mandate safety, kindness, respect and the maintenance of dignity for their loved one with dementia.  |                           |
|  | Yeah, we still go out with people, and now more and more people are being told by me what the problem is because in the beginning I felt like he just would sit there and be pathetic. And like not having interest in what someone was talking about and I didn't want them to think that he just was like, "I don't give a shit. I'm just here with you but I don't really want to be here." But that's not at all what was happening so I told people more and more that what the problem is, and they understand. | The spouse caregiver expresses for the spouse, his desires through interpretation, and alerts others in a respectful way to explain dementia behaviors.   |                           |
|  | I tell him very often I love you. Yes, I love you, and then his eyes light up. It's a good feeling he gets. And even when I'm angry I say, "You know I love you John*." And I just want to make sure things... you're safe.<br>* <i>pseudonym</i>   | The caregiver expresses control over activities to maintain safety; she wants to make sure things are right.  | Variation: Setting limits |
|  | I decide what I think she would like. And of course, we've been married 56 years. So, I have a pretty good handle on what she would like and we do it. And she usually enjoys it.   | Decisions, structure and activities fall to the spouse caregiver. He believes he is competent.  |                           |

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|--|--|--|--|
|  | One of the hardest part – it's actually two of the hardest parts, part A and B, one is knowing how much to help and how much to let her do for herself, you know, how much independence to give her and how much to help, and then that's what makes that, you know, part B of that is that, that seems to be changing almost daily. So, that makes it difficult to keep up. | Caregivers find it difficult to identify potential risks of danger because dementia symptoms are unpredictable. It is a fine line to protect vs. allowing autonomy. The spouse wants to allow the care-recipient the ability to do what she wants.           |  |
|  | That's been difficult because he really wants to drive and he's been good about not doing that. I finally had to say to him, if you get in the car and get behind the wheel, I won't have any choice but to call the police to come and find you because you may get lost.   | Driving reflects autonomy, choice and freedom. Dementia allows the procedural memory to be retained, but disturbs the reaction time and problem solving ability with a significant risk to others on the road. The caregiver has made not-driving a mandate. |  |

| Essential Constituent: 4. I Respond to the Dementia |   |  |                      |
|---|---|--|----------------------|
| Subtheme  | Significant Statements  | Formulated Meanings  |                      |
| Balancing the scale                                 | Because he wakes up in the middle of the night dictating and he comes out with these corporate terms, the other night it was: Intolerable office moral – it wasn't quite like that, yeah. As if you're writing an evaluation. <i>(Laughter)</i> | Humor takes the edge off scary dementia delusions or vivid dreams. The spouses can relax when the silly episode is appreciated by the care-recipient as well as the caregiver. | Variation: Humor     |
|   | So, just every day, it's a challenge of whatever that day has in store for him. So, you have to be very flexible when you have this type of situation. And you have to have a sense of humor. Without it, you can't cope.                       | A sense of humor offers a catharsis when losing control is not an option.  |                      |
|   | So, I go out a little bit every day and I just keep doing what's good for my mental health. I do some yoga, I play tennis when I can and play some golf.  | The spouse caregiver recognizes a dual life and that she maintains good psychological health to continue caregiving in a therapeutic way.                                      | Variation: Self-care |
|   | Right now, this is my world, and whatever I have to do to make things be smooth and calm and for me to keep my sanity, that's what I do.  | The spouse caregiver maneuvers and acclimates to the change with a goal of peace. She thrives on control and the status quo in her dementia world.                             |                      |

|  |   |   |                               |
|--|---|---|-------------------------------|
|  | <p>Spirituality. It's very much a part of mine [my life]. He is not a person that prays, but we just – we went to mass today at 12:05 because he asks to do that sometimes. But we don't talk about prayer a lot. We don't pray together. To me prayer is very personal...he knows that I pray at night...for meditation, just being in the presence is all you really need. Yeah, so I could work with that [if I couldn't go to mass], I could.</p> | <p>Religion and spiritually mindful activities that allow a caregiver to be alone and inclusive of care-recipient. It can be accomplished anywhere.</p>   | Variation: Spirituality       |
|  | <p>I do have a faith. I sit quietly, since we've had good weather, I sit outside and I actually talk to God. I'm thankful for my John*. You can always find something to be thankful for. I do have a faith. I have been very thankful and asked for strength many times. I've been thankful many times because I have it [faith], and I have that strength.<br/><i>*pseudonym</i></p>  | <p>The caregiver uses prayer as a coping mechanism and catharsis to regain inner strength. She is at peace when there is a quiet moment. Religion reinforces kindness, duty and corporal works of mercy.</p>                      |                               |
|  | <p>Church is helping me get through this. I'm a cradle to grave Catholic.</p>   | <p>Catholicism is an external support that allows the caregiver to be the best he can be.</p>   |                               |
|  | <p>To me, the caregiving meeting is very helpful. I feel when I hear someone else talk about their problems or the challenge, and I think that, that happens with us too. So, to hear different people who are going through this, to me it's helpful. Now and then, I'll call another support group member and we talk and she tell me how I had helped her and she has helped me, one on one, ...one on one.</p>                                    | <p>Spouse caregiver uses a support group to learn about the disease, strategies and is able to unload. Talking in a meaningful–cathartic manner, with others who have traveled the dementia path. This contribute to harmony.</p> | Variation: A tapestry of care |
|  | <p>So, I told people more and more that what the problem is and they understand.</p>  | <p>Community engagement allows e a caregiver to share the load, and project sympathy or empathy.</p>  |                               |
|  | <p>The people in the church have been quite a help to me. They always say we are a family within the church</p>   | <p>The church community affords kin relationships which may support respite for the caregiver.</p>  |                               |
|  | <p>I have selected restaurants where I know the owners and the staff very well, and that's where I go because they understand. You really find out quickly who your real friends are, you know what I mean? And I'm not going to be judgmental on people because for most of them, this [dementia disease] is very foreign to them and they don't know how to deal with it.</p>   | <p>Caregivers appreciate support from family, friends and neighbors, even businesses, who understand and engage in the dementia journey without reservation.</p>  |                               |

|  |  |   |  |
|--|--|---|--|
|  | <p>I want to mention is the role of our family dog, Duffy, a 5 1/2-year-old Labradoodle. He is probably the key person– K-9 in taking care of [my wife]. He [the dog] can instantly diffuse a potentially ugly situation and be the best companion for the patient and the caregiver. I think this is something that may be underplayed in the treatment and management of a household dealing with this horrific illness.</p> | <p>Pets are increasingly part of the family and marital dyads. They can provide a calming influence, allow expressive touch via petting and holding, and are therapeutic as <i>someone</i> to talk to and an incentive to walk.</p> |  |
|  | <p>Bindi (the cat) ... I know she helps, yeah. And John*, very much John*. Probably more John* than me, because she'll sit next to him...<br/>* <i>pseudonym</i></p>   | <p>The cat provides a therapeutic milieu with her presence.</p>   |  |