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**BOUND AND DETERMINED:
THE PHENOMENOLOGY OF HUSBANDS CARING FOR
WIVES WITH DEMENTIA**

By

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B.S., Nursing, University of New Mexico, 1988
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DISSERTATION

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ABSTRACT

The lived experience of husbands caring for wives with dementia was investigated in order to develop a better understanding of their caregiver burden. The conceptual background for the study originated in the work of philosophical phenomenologists Edmund Husserl and Edith Stein with particular attention to their theories of inter-subjectivity and empathy. Amadeo Giorgi's Descriptive Phenomenological Method in Psychology was used for study design and analysis. Results suggest an enduring connectedness of the couples and their bonds throughout the shifting of roles and emotions as the dementia progresses. Implications for nursing include the need to employ interventions respectful of the persistence of affective awareness in those with the dementia even towards end-stage and the resulting importance of situational assessment of decisional capacity.

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Chapter 1

Introduction

Purpose

The proposed research is motivated by concerns for the gulf between the medical and social presentation of dementia and the way people with dementia (PWD) and their caregivers experience the disease, particularly the subset of married couples in which the husbands care for wives with progressing dementia. The purpose of the research is to develop a phenomenological description of the experience as lived by five spousal dyads—women with dementia and their caregiver husbands who must consider or transition from only homecare to using adjunct adult day care services. The research questions are:

1. What is the meaning of dementia to husbands caring for their wives with dementia?
2. What is the meaning of dementia to wives receiving care from their husbands?
3. What is the meaning of dementia spousal care giving/care receiving with respect to nursing care?

Background and Significance

The medical construction of dementia is a clinical syndrome of loss and decline in memory and other cognitive faculties. Alzheimer's disease represents approximately 60–80% of dementia cases (*Alzheimer's Facts and Figures*, 2012). The *Diagnostic and Statistical Manual of Mental Disorders*, fourth edition (*DSM-IV-TR*; APA, 2000), 294.1x, defines criteria for “dementia of the Alzheimer's type” as cognitive deficit with memory impairment and at least one of the following cognitive disturbances: aphasia: language failure, apraxia, intentional failure (inability to manipulate a zipper), agnosia (the failure to recognize common objects (wondering what a fork is), and problems of executive function

that result in problems with managing daily living. This cluster of symptoms cannot be explainable by nervous or systemic conditions and must have occurred gradually.

The World Health Organization (WHO, 2011) estimates 29 million cases of some form of dementia worldwide, with an associated Global Burden of Disease comprising 11.2% of all disabilities in people 60 years and older. Alzheimer's disease and other dementias (AD) affect an estimated 5.4 million Americans, and 12 % of those 65 and older (Alzheimer's Disease Facts and Figures, 2012). The U.S. figures have doubled since 1980. (Hebert, Scherr, Bienias, Bennett, & Evans, 2003). Of all people with Alzheimer's in the US, 4% are younger than 65 and 45% are 85 or older. The risk of AD rises as the population ages and the incidence of AD is predicted to increase. A recent report from the Alzheimer's Association (2011) characterizes AD as "the defining disease of the baby boomers". The total number of people age 65 and older with AD and other dementias is estimated to reach 7.7 million in 2030, at least a 50% more than the 5 million currently affected (Hebert et al., 2003; Plassman et al., 2007).

At any given time, 80% of people with dementia (PWD) are living at home and are cared for by family caregivers, primarily spouses or children. Family members experience economic and emotional challenges in assuming these responsibilities (*Alzheimer's Disease Facts and Figures*, 2012). In 2009, 15.2 million unpaid caregivers tended to PWD, representing an average of 17.4 billion hours of nonprofessional care, with 32% having been caregivers for over 5 years (*Alzheimer's Disease Facts and Figures*, 2012).

These statistics demonstrate an alarming situation and one that is recognized by the National Institute of Nursing Research (2009) as evidenced by their Mission and Strategic Plan, which supports research that addresses quality of care issues of the elderly,

improvement in transition between care settings and factors that relate to the burden of informal caregivers.

Although the majority of PWD are living at home, the trajectory of the illness is a progressive decline leading to need for increasing levels of care. On average, PWDs live 8 years post diagnosis (National Institute on Aging, 2008). Though 88% of Americans age 65 and older report that they strongly prefer to remain in their own homes as they age (Keenan, 2002), most people with dementia eventually require nursing home care when families feel they can no longer handle the burden at home (Smith, Kokmen, & O'Brien, 2000). Nursing home placement is associated with faster decline, although this is mitigated by prior adult day service use (Wilson et al., 2007).

Major factors influencing transition to nursing homes are PWD depression, infrequent socializing, (Cohen-Mansfield & Wirtz, 2007), dangerous behaviors occurring while up wandering at night, (Yaffe et al., 2002), and mood and behavioral disturbances (Auer, Monteiro, & Resiberg, 1996). Transitions also occur when families simply feel they can no longer handle the burden at home (Smith, Kokmen, & O'Brien, 2000).

Adult day services (ADS) provide a transitional step to nursing home placement (Gaugler et al., 2003; Zarit, Gaugler, & Jarrott, 1999) and can delay placement in nursing homes by supporting family or nonprofessional caregivers (Gaugler, Kane, Kane, & Newcomer, 2005). These services are community-based programs that offer individualized, therapeutic activities and services in group settings for older adults who have a variety of disabilities, including an estimated 50% with some type of dementia (*Alzheimer's Disease Facts and Figures*, 2012).

The first program was a geriatric day hospital in Greensboro, North Carolina established in 1960 that gradually developed services to meet the respite needs of client's caregivers. Today there are more than 4,600 ADS centers nationwide, 80% have nursing staff and 50% have a social work professional (Abraham, 2000). In addition, the evolution has been towards a dementia focus with 90% offering some kind of cognitive stimulation program or memory training. The average participant is a 65+-year-old white female with dementia who requires assistance with at least one activity of daily living (ADL), and averages 2 years of enrollment (O'Keefe & Siebenaler, 2006).

Survival and quality of life of PWD have been associated with the well-being of the caregiver (Dang, Badiye, & Kelkar, 2008) but the type of association and contributing factors continue to be uncovered. *Caregiver stress* is considered a significant problem among those who care for PWD. Caregivers are reportedly more likely to be depressed or angry than a demographically matched comparison group (Vitaliano, Zhang, & Scalan, 2003), and have higher rates of mortality than non-caregivers (Schulz & Beach, 1999). The chronic stress of caring for PWD has been associated with cardiovascular disease risk and hypercoagulability (von Känel et al., 2010; von Känel et al., 2011).

Behavioral and psychological symptoms of dementia are considered among the most difficult stressors caregivers face (Woodhead, Zarit, Braungart, Rovine, & Femia, 2005). The behavioral and psychological symptoms of dementia also are reported as major factors in the increased burden on the caregiver (Donaldson, Tarrier, & Burns, 1997; Fitz & Teri, 1994; Gaugler, Edwards, Femia, Zarit et al., 2000; Hope, Keene, Gedling, Fairbugn, & Jacoby, 1998), and this burden is greater than those caring for same-age elders without dementia (Gaugler, Kane, & Newcomer, 2007).

Kasuya, Polgar-Baily, and Takeuchi (2000) define *caregiver burden* as a “multidimensional response to physical, psychological, emotional, social and financial stressors associated with the caregiving experience” (p.119). The idea of measureable “burden” related to care giving was developing in the 1960s (Lowenthal, 1964), but the concept was operationalized to measure the subjective weight of discomfort and concern the caregiver feels caring for PWD (Zarit, Reever, & Bach-Peterson, 1980).

My proposed research is situated in this area of informal care giving and burden. Relocation to care facilities has profound symbolic meanings connected to dependence and end of life (Aminzadeh, Dalziel, Molnar, & Garcia, 2009). I have chosen to study the meaning of dementia to married couples contemplating the intermediate step of adult day service to better understand the concerns that caregivers and those with dementia experience, and the meanings they find or make in response to their situation. My interest is in the participant’s active construction of subjective and intersubjective social knowledge of dementia.

Conceptual Framework

We live in a complex information age in which challenges to our understanding of nature and humans are routine. If we do not understand the dynamics of personhood and disease within the medical system phenomenologically, socially, and politically (Scheper-Hughes & Locke, 1987) we risk a myopia that sees only the prevailing paradigm. The prevailing paradigm for dementia is the description given above. The concept of “Alzheimer’s disease” as a clinical-pathologic entity separate from senile dementia in the elderly is a product of the late twentieth century. Alois Alzheimer was a neurologist working in the new field of psychiatry in 1907 when he presented the case of a 51-year-old woman he

saw in 1901. Her family brought her to him because she had developed memory problems, paranoia, and difficulty speaking and understanding words (Maurer & Maurer, 1998). Her symptoms rapidly grew worse and she died. Alzheimer performed an autopsy that revealed dramatic shrinkage in her brain, widespread fatty deposits in small blood vessels, and abnormal circum cellular deposits that are now called plaques and tangles and have become pathognomonic of the disease. Since actual diagnosis requires presence of these tangles the only definitive diagnosis is by autopsy, thus the diagnosis becomes presumptive, based on different systems of presenting signs and symptoms (Hoozeman et al., 2009), but the cause is seen as the neurofibrillary tangles.

Phenomenology, the philosophical framework for this study, was developed by Edmund Husserl (1859–1938) as a critique of *nominalism* and empiricist theories of abstraction (1900/2001, *Logical Investigation II*). In general, nominalism holds that there are no abstract essences just qualities that belong to members of the same category—there is no abstract red apart from examples of objects that are red within the category, *red* (Morehouse, 1989). In *Crisis of the European Sciences* (1954/1970), Husserl argues the way Galileo quantified and mathematized nature can leave phenomena with only superficial, abstracted, symbolized meaning, unless the original meaning is kept in mind. A measurement is an abstraction of the experience. For example, Husserl frequently used the example of a plum tree. The mental acts that occur by living through the experience of the plum tree could be, I smell this blossoming plum tree or I hear the rustling leaves as I look at the plum tree. The height or weight of the tree, its color location on light wavelengths, or speed of the wind causing the rustle, are the abstractions removing the tree from the experience. With respect to dementia, the way it is lived and experienced should be the grounding of dementia science.

The biomedical model of dementia is an example of a type of *mathematization*. It is a social construct focusing medicine on a physiologically technical orientation of labeling diagnostic cause, which reduces a patient's experience to that label, which then becomes (rather than the symptoms as experienced by the patient) the focus of the *cure*, separating the disease from the patient. This becomes problematic. Cause, cure, and treatment are intrinsically connected. Findings from the Nun Study (Snowdon, 2003), a longitudinal natural history of aging and disease, have shown that those with the same type, location and degree of neuropathologic lesions had a wide range of clinical symptoms—from none to severe, suggesting to the authors that the brain has a capacity to resist pathology. Knopman et al. (2003) found no correlation between amount of AD pathology and cognitive compromise in a study of 39 cognitively normal elderly.

Ideas and philosophies represent different hegemonic currencies and promote views of “normal” based on who has power and how they share it with a resultant social construction of illness and disease (Scheper-Hughes & Locke, 1987). A bio-medical view of health is a *disease* perspective that describes a patho-physiologic process, as opposed to illness as the subjective and day-to-day meaning of that experience, and in doing so gives power over the described entity, in this case, dementia, to medical providers to define and determine meaning.

The political construction of dementia within the medical system has been extensively documented (Ballenger, 2000, 2006; Conrad & Schneider, 1980; Whitehouse et al., 2000). In *From Senility to Alzheimer's Disease: The Rise of the Alzheimer's Movement*, Fox (1989) argues persuasively that the view of dementia shifted to a biomedical perspective as a result of a social movement. The movement involved the intersecting needs of research

scientists and the National Institute on Aging (NIA) for funding, and the interests of caregivers, scientists, and NIA representatives in the formation of an advocacy organization (Alzheimer's Disease and Related Disorders—precursor to the Alzheimer's Association) in the 1970s. The shift from the earlier twentieth century view, which at first only included a premature senility (*dementia praecox*) and later encompassed *symptoms* which had been considered normal, was necessary to further the argument that Alzheimer's disease is a major killer. The argument rests on the assumption that Alzheimer disease and senile dementia are a single process and, therefore, should be considered a single disease. When conceptualized this way, Katzman (1976) was able to claim Alzheimer's disease to be a fourth or fifth leading cause of death; yet it was not represented in any United States Vital Statistics mortality categories. A review of mortality statistics for 2008 (Minino, Xu, & Kochanek, 2010) indicates Alzheimer's disease is the sixth leading cause of death listed on death certificates.) Fox (1989) further elaborates on the growing field of neuroscience at that time and the impact of the electron microscope in visualizing pathology. By focusing on a particular disease, which was a leading cause of death made it easier for the NIA to attract funding.

Lyman (1989) critiqued bio-medicalization of dementia calling for a sociogenic approach, which views people with dementia as social actors in socially constructed environments given socially constructed knowledge about aging, human development and disease. How we act and label is a social script. Vayda, Patterson, and Whitehouse (2010) were still calling for a reconceptualization of dementia, observing that most elderly with dementia present with mixed patterns of pathology, medications remain with meager effect

and general population physical and nutritional fitness, as well as ways of enhancing community and cognitive engagement show greatest potential for prevention.

In the gerontologic nursing literature (Buron, 2008; McCormack, 2004; Penrod, Yu, Kolanowski, Fick, Loeb, & Hupcey, 2007), a commonly used and cited theory for understanding dementia is one developed ethnographically by Kitwood (1997), and is the basis of Patient Centered Care (PCC). Kitwood's theory is that dementia is a process experienced within a psychosocial environment. He proposes that maintaining personhood through the declines of the mind/body is essential to treatment. Kitwood hypothesizes social psychological *and* neuropathological factors together affect the dementia experience and a "malignant psychology" undermines people with dementia, in effect, contributing to functional decline as much as any neuropathological degeneration. Kitwood (1997) describes the dialectic between neurologic impairment and "positive person work" (p. 68), in which personhood of those with dementia can be preserved by skilled intervention of caregivers. PCC seeks to support the *relational* aspects of personhood, suggesting that social reconstruction can provide an environment that aids the expression and production of self through an unwavering commitment to the *person* with dementia to the last. He attempts to restructure the fractured world of the patient by providing a nurturing environment. McLean (2007) studied "behavioral problems" of nursing home residents in the context of communication and concluded that their *agency*, their help seeking behaviors and actions were pathologized in a serial depersonalization as their disease progressed. Bourbonnais and Ducharme (2010), found screaming behavior to be related to vulnerability, suffering, and loss of meaning, that each person's screams are like a unique language that can be learned.

Anthropologist Lawrence Cohen (1995), who did field work in India, wrote about the difference between the globalizing American-European and local Indian gerontologies. The American-European social construction is “a discrete, virulent and unambiguous form of pathology” (p. 315). In his comparison study of four neighborhoods in Benares (in Uttar Pradesh, India) to three western cities, Cohen looks beyond a model of senile dementia rooted in neuropathology and genetics to describe what is at risk in the perceptions and attributions of behavioral differences in old age. In Benares (1995), memory loss itself—“weak brain”—is commonly associated with old age, but wandering, yelling, and anger are most often seen as a result of “bad families” and connected to views of the responsibility of children to their parents within strong families. Cohen defines the concept of a heuristic of senility as:

The attribution of difference or discontinuity to an old person, or to old people as a group, when that difference is embodied in terms of organs, or states of volition, affect, character, or cognition, when that difference is marked by others in terms of the behavior—actions or utterances of an old person (1995, p. 317).

The crucial issue here is that the political and cultural aspects of attribution should be identified and examined when the impact on lives is so great. This is a possible example of the distinction between the type of nominalism Husserl critiqued and phenomenology, when categories and taxonomies influence perceptions and attributions instead of the other way around. Focus on the experience of people living the phenomenon of interest understands that personhood, the phenomenal body/self is also socially constructed, the assigned value of persons by their community (Scheper-Hughes & Locke, 1987) and a gauge of how an individual is valued in relation to the group. For example, Menkiti (1996) suggests that

within an African view of personhood one's self arises within the language and gene pool of their community. They are not given personhood as a result of birth or conception, but as a process of interaction within the community. This occurs with ritual and social transformation that accords value to the progression. In our society, the advent of prenatal sonograms has made it commonplace for fetuses to have names and possessions, but issues in the valuing of our elderly remains controversial. Stephen Post (2000) criticizes the concept of Alzheimer disease as an objective medical entity from an ethical standpoint suggesting that we live in a "hyper cognitive society" where our worth and "personhood" is based on self-control, independence and economic productivity, at the expense of emotional, relational, aesthetic and spiritual qualities: "Very simplistically, 'I think, therefore I am,' implies that if I do not think, I am not" (p.247).

These are just some of the complexities when considering dementia from political and sociologic viewpoints. It is also why the experience of dementia apart from its representation becomes of interest and why phenomenological study is appropriate.

Phenomenological research. Phenomenology has been identified as a philosophical framework useful for the study of the lived realities of those receiving nursing care (Lopez & Willis, 2004; Meleis, 2007; Paley, 1997). Husserl (1950/1999) originated phenomenology as a philosophy of philosophy and imagined it as the necessary basis for any science. It is the study of consciousness (1954/1970). Although Husserl critiqued empirical science as it was being practiced it must be emphasized that his phenomenology is philosophical; social science researchers have developed the phenomenological method for science. I used a method that was developed by Amadeo Giorgi (1985, 2009). Table 1 is a glossary of the language used to describe phenomenology. In the context of dementia, our lifeworld is

socially constructed and represents different versions of appearances. Phenomenology is unconcerned with the fact of any of these claims because the purpose is to understand the way consciousness is directed toward and intends the phenomena of interest, and the way that leads to our synthesizing meaning from experience.

Table 1.1 Key Terms

Term	Definition	Source
Consciousness	The focus of phenomenological study, the directed mental acts of the ego/self/body, as in our stream of consciousness	Ideas I, pp. 64–65
Constitution	The mental process that “bestows” sense	Ideas I, pp. 127–129
Empathy	An act of perceiving another’s consciousness where we are at the foreign subject, turned with it to its object	Stein, 1989
Eidetic Variation	A process of grasping the essence (eidos) by imagining instances of the phenomena in order to distinguish universal from personal	Ideas I, pp. 7–15
Intentionality	The directedness of the subjective being toward the appearance and actuality of the phenomena, the mental act of imagining a dragon	Ideas I, p. 73
Intersubjectivity	Objects in the lifeworld are available as intentional objects to others; intersubjective constitution of the world requires empathy, the ability to put ourselves in another’s position. This is our access to objectivity.	Ideas I, sections 150–152 Husserl, E. (1950/1999). <i>Cartesian meditations</i> . Meditation V
Lifeworld	The venue in which we extend our consciousness, physical and socio/cultural selves, everyday life	Husserl, E. (1954/1970). <i>The crisis of European sciences and transcendental phenomenology</i> . (D. Carr, Trans.). Part III A, sect. 29
Natural attitude	Naïve general positing of the world from sensual experience, it is pre reflective, pre-analysis	Ideas I, pp. 50–53, 81–85

Table 1.1 Key Terms (continued)

Term	Definition	Source
Phenomena	Whatever appears or occurs to us	Husserl, E. (1913/1983). <i>Ideas pertaining to a pure phenomenology and a phenomenological philosophy First Book</i> . (Ideas I) Introduction Husserl, E. (1900/2001). <i>The shorter logical investigations</i> (J. Findlay, Trans.) p. 95–96
Phenomenological reduction	Technique for the practice of phenomenology, also known as Epoche or bracketing. A shift from the natural to the phenomenological attitude so that consciousness of and not the object itself becomes the focus of investigation	Ideas I pp. 60–66
Phenomenology	The systematic study of the sphere of consciousness as it is directed towards phenomena (i.e. if the phenomenon is a tree it is the object of consciousness but phenomenology is interested in how the object is experienced, consciousness of the tree)	Ideas I, Introduction
Sense	The ideal intentional content of an act of consciousness (doctrine is a form of sense) sense expressed in language is "meaning"	Ideas I Chapters 5 & 6

Phenomenology as a science is a rigorous process of managing subjectivity, of accepting the premise that there is no alternative to our subjectivity because everything we know is from our self and the flow of our experience. What we know is inseparable from our being. There is no Archimedean point to which we can abstract ourselves and see clearly from a perspective of objectivity. Experience is the basic data for building science. The things or feelings that our consciousness turns toward are phenomena.

One of the major divergences of phenomenology as science as opposed to philosophy is the application of the phenomenological reduction towards another's experience (Giorgi, 1985, 2006, 2009). Phenomenologically, the subjectivity of others is a necessary feature of

our constitution of objectivity via empathic inter-subjectivity. This is derived first from self-evidence of our own embodiment (for example, we can touch our hand as an object, revealing an interiority–toucher, as well as exteriority–touched, and we are mobile in that we can change location from “here” to “there”) making us objects in the lifeworld (Husserl, 1950/1999). Others are objects in the lifeworld as well as subjects for the world, who at the same time experience us as others. “I experience the world (including others) and according to the experiential sense, *not* as (so to speak) my *private* synthetic formation, but as other than mine alone [*mir fremde*], as an intersubjective world, actually there for everyone, accessible in respect of its Objects to everyone” (p. 91). Merleau-Ponty (1945/2008) writes, “In the cultural object I feel the close presence of others beneath a veil of anonymity. Someone uses the pipe for smoking, the spoon for eating, the bell for summoning, and it is through the perception of a human act and another person that the perception of a cultural world could be verified” (p. 405). This leads to the “intersubjectively identical thing,” (Husserl, 1913/1983, p. 363), a common understanding or temporal synthesis mediated by empathy, a necessary condition for consciousness. Stein (1989) describes empathy as the way we imagine and enter another’s mental life. The content of their mental act becomes the content of our mental act in their place. Our consciousness is in this lifeworld, perceiving and elaborating perceptions into beliefs and judgments as well as contributing to social constructions and “we” experiences. Our natural attitude as a perspective is a function of our indoctrination and a feature of subjectivity. The phenomenological attitude is assumed by “bracketing” the lifeworld. To study phenomena, the intentional object itself is bracketed, focus shifted to the process through which the phenomenon enters our consciousness and away from the object of consciousness. Thomasson (2005) describes phenomenological

bracketing as a cognitive transformation from world oriented experience to self-knowledge of those intentional states making up our worldly experience.

Phenomenological research interrogates the subjective experience to access the objective, non-personal, essential aspects of phenomena. According to Husserl (1900/1970) “...we are concerned with a phenomenological origin...insight into the concepts involved, looking methodically to the fixation of unambiguous, sharply distinct verbal meanings...through knowledge of the essentiality of the elementary concepts present in them, and of the concepts of their forms of combination (p.79).” To understand this, Sadalna and Adorno (2001) recall Picasso’s *Metamorphosis of a bull*, a series of eleven drawings of a bull from a fleshed out beginning drawing to the final one consisting of nine lines essential to the structure of the bull. In a similar fashion, the phenomenological researcher obtains versions of the experienced phenomenon from different subjects to distill the essential elements or essence of the experience.

Phenomenology and nursing. When human uniqueness and inter-relational caring become central to inquiry, it research requires a different orientation, ethic, and starting point for its descriptions (Watson, 2012), separate from the empirical sciences. Watson sees nursing theories as presentable on Cartesian coordinates of two axes: concrete to abstract, and static to dynamic, and suggests that traditional science is more amenable to the directions of concrete and static. Science aimed at building knowledge of human caring, health, illness and lived experience falls in the abstract-dynamic quadrant primarily because human being occurs in a context of choice, responsibility, sociocultural history and an ontology of holism.

Dreyfus (1994) describes, “caring” (not unique to nursing) as an existential skill, and nursing, as an enterprise of caring that requires entering other people’s lives. This inter-

subjective world consists of mind, thoughts, consciousness, values, feelings, emotions, actions, purposes, languages, beliefs, arts, and institutions (van Manen, 2007). Watson (2012) articulates the difficulty of developing a nursing science that takes into account the essential mystery of human being.

Diversion from empirical processes is a controversial area in nursing science. An especially strong critic, Paley (2002) sees the move towards “caring science” as a dismantling of boundaries in a struggle against medical models of empirical science resulting in the promotion of favoritism, injustice and self-deception. Paley references Nietzsche’s *On the Genealogy of Morality* (1994) in his rejection of an ideology of compassion as an ethic, an expression of antagonism (towards medical science), motivated by resentment and lacking integrity. His particular objection is the *privileging* of evidence.

What nursing calls phenomenology... abandons any pretense to scientific rigor, procedures are virtually non-existent; generalizability is not even aspired to; explanation, confirmation, and quantification are systematically disowned; and, in a final dismissive gesture towards objectivity, ‘multiple realities’ are permitted (Paley, 2002, p. 29).

One error in this view is that the fact of the phenomenon is neither what this view of nursing is nor what the phenomenological method aspires to. The interest is the way the phenomena are experienced, therefore making most human utterances and gestures of lived human experience phenomenological evidence. *How* one is ill is a socially negotiated process apart from any measurable facts.

Nursing science has had a difficult history with phenomenology. Dinkel (2005) identified 18 different methods of phenomenological inquiry used in nursing based on different permutations of the paradigm. In general, the point is a detailed description of a

phenomenon, based on narratives transcribed from semi-structured interviews of those who can express a particular experience.

Phenomenological researchers should follow both a philosophical and methodological process to maintain rigor, yet often the underpinnings of nursing phenomenology are divergent most often evolving from the philosophies of Husserl or Heidegger often intermingled or not delineated (Dowling, 2007). I think this suggests support for Paley's argument; frequently philosophies and methods are often blended. This means that what we call phenomenology in nursing research can be improved with a consistent philosophical base and clearly delineated processes to provide rigor to the developing description of experience.

Another aspect of the controversy in nursing science seems related to how central pathophysiology is to the particular nursing process and how nursing is defined. Paley views nursing concretely as the management of recovery and rehabilitation. Critical care or emergency nursing requires focus to identify acute changes in airway breathing and circulation and other immediate threats to the life of the patient. This fits in well with Paley's view.

Watson (2012) quotes Gadow's (1984) definition of caring as, "...the moral ideal of nursing whereby the end is protection, enhancement and preservation of human dignity" (p.38), and goes on to say that all human caring is related to knowledge of intersubjective human responses to health and illness conditions. On Watson's suggested Cartesian order, Paley is firmly within the concrete, static quadrant while Watson is in the abstract, dynamic one. In chronic and palliative care nursing, the inter-relational caring aspect of nursing widens our vision from primarily pathophysiological, and at the same time, narrows it to the

particular expression of what it is to be the particular person who is your patient. (S)he is not just a venue for illness or a host of disease but a complex organism with values, goals and interactions from the microscopic Krebs's cycle, to dynamic interchange with family, social, political and physical environment. This is the essential tenet of the unitary view of nursing theory held by Watson (2012), Rogers (1994) and Newman (1994) among others. This perspective is particularly amenable to phenomenology.

Newman (1994) for example has a concept similar to bracketing and eidetic variation in relation to health and nursing. She conceives of health as expanding consciousness, (consciousness being the information within a system) and the ego or self as having the capacity to either constrict (similar to remaining in the natural world and preferring the unreflected) or expand—conceivably the phenomenological analysis leading to transcendental inter-subjectivity, although she describes it as transcending ego boundaries. The catalyst for this transcendence of ego boundaries (phenomenological reduction) is disequilibrium or pattern disruption. Illness as one of these patterns is the point of nursing intervention. Nurses intervene when the natural attitude is disturbed. The goal is to work with the patient to identify the underlying pattern disruption and work to achieve reintegration.

Omery (1983) was among the first writers on phenomenological method as an alternative to quantitative methods, which she saw as often abstracting and reducing human qualities that should be studied within the context of living. She described six steps as necessary for any phenomenological method: descriptive phenomenology as free from preconceived notions as possible, probing of the phenomenon for essentials, exploration of the different ways phenomena manifest, exploring the way consciousness constitutes

phenomena, bracketing (by which she means examining the phenomenon outside of context), and hermeneutic analysis. Although she lists these as essential, she also notes that as an inductive descriptive, hermeneutic process, phenomenology resists regimented procedural steps. Method continues to evolve because capturing the essence of experience requires accounting for the ambiguities of human being.

Giorgi (2009) is an experimental psychologist who developed a method for phenomenological research based on the philosophy of Husserl, in response to his observation that natural science research methods tended to reduce human beings and their experience to the level of physical things, which is only effective for studying some aspects of human being and not for the way we designate value, quality, or meaning (as in intentionality).

In my research, I audio-recorded interviews of couples and collected data to understand the way they construct views of their situation and synthesize meaning. I used Giorgi's descriptive phenomenological approach as a guide to ground knowledge about dementia, dementia caregiving and receiving, and a deeper understanding of the experiential meaning of couples so engaged.

Conclusion

This chapter presented a broad overview of the background, theory, and plan for researching the experience of dementia as lived by spouses. In chapter 2, I present a literature review of research into the meanings and lived experience of dementia and spousal care giving. In chapter 3, I outline the procedure, method, and methodology of the research as well as the assumptions and limitations.

Chapter 2

Literature Review

This literature review is a systematic identification and critical analysis of previous research relevant to the purposes, focus, and methods of this study. The databases used for searching include PubMed, CINAHL, PsycINFO, and the compiler, ProQuest.

Experience has a particular meaning in the context of phenomenology. It is an act of consciousness that represents the object of consciousness. The same object of consciousness can have different meanings, as demonstrated in the literature. For the purpose of this study, it represents dementia from the perspective of care giving and receiving among married couples. The predominant focus is the meaning of relationship, marriage, or caregiving within the domain of dementia. Shanley, Russell, Middleton, and Simpson-Young (2011) stated that their study focused on the experiences and needs of family caregivers of those with end-stage dementia. However, their focus was not on the dementia itself. Their focus was on "... getting support; having to trust others with care; managing the loneliness of being a carer; witnessing a loved one fade away..." (p. 325). My research was aimed at finding meaning in caregiving or making sense of a relationship transformed by dementia—how it presents initially, narrowly, before it is put in the greater context of personal attributes or relationship styles.

What follows is an overview of the study of dementia caregiving, particularly burden and benefit, to set the historical context. I have reviewed studies of male caregiving, studies related to personal experiences of having dementia, studies that combine for a dyadic perspective of couple-hood, followed by studies seeking to integrate multiple factors or systems toward a more a holistic view. Throughout the review, the theme of meaning-

making by way of inter-subjective appraisal is evident and calls for a more detailed discussion of the role of empathy in phenomenology, which is address in the final section of this chapter.

Burden and Benefit

The impact on emotional and physical health associated with providing ongoing care to a family member with dementia was first explored in detail by Grad and Sainsbury (1963). Their study investigated the effects homecare of the mentally ill had on the people they lived with finding that the patients who affected families the most severely were those with dementia. Caregivers take on additional physical work of household chores as well as being exposed to symptoms of depression, anger, agitation, and paranoia in their care recipients (Teri et al., 1992). These affects and behaviors intrude on their lives (Siriopoulos, Brown, & Wright, 1999) over a period of months to years, because people with dementia live an average of 8 years post-diagnosis (National Institute on Aging, 2008).

As Alzheimer's disease and related dementia (ADRD) progresses, caregivers must continually monitor their care recipients and witness their cognitive deterioration, ultimately caring for someone who no longer recognizes them. This exposure to chronic stressors can lead to psychosocial distress and risky health behaviors (Croog, Burlson, Sudilovsky, & Baume, 2006).

Wilson (1989) conducted a grounded theory study of family caregivers of persons with dementia (relationships not specified) who had been caring for their family member more than six weeks and less than three months prior to the interview. Her purpose was to conceptualize the course of ADRD as experienced by family caregivers. She found a pattern of response she characterized in eight stages: Noticing, Discounting and Normalizing,

Suspecting, Searching for Explanations, Recasting, Taking It On, Going Through It, and Turning It Over.

The act of *noticing* was described by the participants retrospectively, as the clues in behavioral or cognitive behavior of their family member indicated a developing worrisome change. *Discounting and normalizing* occurred as the noticed changes were denied significance and attributed to old age or emotional upset until a particular event occurs or behavior worsens to the point it can no longer be rationalized. This is the beginning of the next stage, *Suspecting* something more serious is going on. *Searching for an explanation* is the stage of diagnosis, and *Recasting* is a process of reappraisal. *Taking it on* is conceptualized as the process of shouldering responsibility for care of the family member in light of the knowledge of diagnosis and prognosis. *Going through it*, is the stage of learning how to be a caregiver and doing it until the last stage, *Turning it over*. Wilson describes this stage as ending primary care and control of the family member, usually through institutionalization.

Lindgren (1993) described spousal caregiving to those with dementia as “a fatalistic career” (p. 214), because the daily activities and obligations of caretaking are determined by the demands of the spouse. In a grounded theory study of ten spouse caregivers (six wives, four husbands) who had provided care between 1 and 9 years, Lindgren identified three stages. All involved learning new roles, adapting to patient demands, and restructuring their lives. *Encounter*, the first stage involves learning the diagnosis and the expected decline, and adjusting to the impact of a substantially altered future. *Enduring*, the second stage, occurs after the caregiver has taken on the role of caregiver and has established caregiving routines and developed management skills. This stage occurs when caregivers become socially

isolated as they become enmeshed in their caregiving role. It includes loss of companionship and reciprocity, management of behaviors, wandering at night, incontinence, grooming, feeding as well as the routine activities of managing a home. The third identified stage is *Exit*, which is the point when the caregiving role has reached such intensity that it is ended either by the patient's death or institutionalization. This staging does not seem too different from Wilson's study. Her first five stages would fit into Lindgren's *encounter* stage; stages 6, taking it on, and 7, going through it, fit into Lindgren's *Enduring* stage; and Wilson's *turning it over* describes Lindgren's *exit* stage.

Jansson, Nordberg, and Grafstrom (2001) raised the concept of "invisible" caring from their grounded theory study of eight spouses providing the majority of care for their partners in their homes (2 of the 8 were male carers). By observation, they found four broad caring themes: ADLs, communication, supervision/ surveillance, and activity/stimulation. These observations were supplemented by open-ended interviews with both partners, although the responses from those with dementia were not used because the dialog "...often dealt with past memories" (p. 807). Within the theme of communication were the categories of empathy/thoughtfulness and nearness. These were qualities of the caring not captured by observing instrumental care, and therefore the "invisibility." This included "entering their partners' feelings and illness, enhancing their spouse's self-esteem, thereby protecting their identity" (p. 808).

The goal of this study was to describe the activities carried out in caring for a spouse with dementia, so the invisible aspect was not investigated further. The researchers found that spouses often guided their partners toward activities that provoked an affective response,

knowing that the memory of the activity may be gone, but the capacity for enjoyment remained.

The most predominant finding in the literature on caregiving related to dementia is the idea of *burden*: a multidimensional psychosocial response to the physical, emotional, social, and financial aspects of caring for another (Kasuya, Polgar-Baily, & Takeuchi, 2000). Burden has been found to be higher in those caring for people with dementia than those with other illnesses (Alzheimer's Facts and Figures, 2012; Brodaty, 2007). Research on the idea of burden related to care giving was developing in the 1960s (Lowenthal, 1964). The 22-item version of the *Zarit Burden Inventory* (ZBI) (Zarit, Orr, & Zarit, 1985) is the instrument most consistently used in dementia caregiving burden research (Bédard, Pedlar, Martin, Malott, & Stones, 2000). Bédard et al. (2001) devised a shorter, 12-question revised form of the *Zarit Burden Interview* (ZBI), which has been used to measure change in burden over time (Bédard, Molloy, Pedlar, Lever, & Stones, 1997), as well as interventions aimed at reducing burden (Dias et, 2008). These “burden” interviews generally are self-appraisals of caregivers, regarding the impact care giving has on health, privacy, extent of impact on social life, feelings of guilt, anger or strain when around the cared for, personal control, and proficiency.

This view of burden and stress has been expanded upon by other studies that looked at gender and world perspective. Sense of coherence was found to be higher in male spouse caregivers who also reported less depression (Valimaki, Vehvilainen-Julkunen, Pietila, & Pirttila, 2009) and the least amount of burden was reported by husbands, when comparing husbands, wives, daughters, and sons (Conde-Sala, Garre-Olmo, Turro-Garriga, Vilalta-Franch, & Lopez-Pousa, 2010). Danhauer, McCann, Gilley, Beckett, Bienias, and Evans,

(2004) found considerable variability in patterns of caregiver depressive symptoms over time but no systematic increase in distress despite increased severity of dementia symptoms. This pattern is consistent with some previous reports (Gaugler et al., 2000) and with the view that distress in dementia caregivers may reach an asymptomatic plateau as caregivers adjust to stressors (Powers, Gallagher-Thompson, & Kraemer, 2002). Yeager, Hyer, Hobbs, and Coyne (2010) found that psychiatric symptoms of the PWD, not primary dementia diagnosis, result in varying burden response. Braun, Mura, Peter-Wight, Hornung, and Scholz, (2010) found that dementia caregivers whose husbands used more positive communication reported less depression and distress. Pearlin, Mullan, Semple, and Skaff (1990) proposed caregiver stress as a dynamic process, involving socioeconomic characteristics and resources, feelings of mastery, competence, management of meaning, situation, distress, role captivity, relational deprivation, and loss of self. Other studies (e.g., Park, 2010) emphasize the role that meaning-making has in the appraisal of stress. Hellstrom, Nolan, and Lundh (2005, 2007) found that successful living with a spouse with dementia had to do with maintaining couplehood.

Schulz and Beach (1999) conducted a 4-year study that compared a group of 392 elderly caregivers to a control group of 427 to examine associations between levels of burden and caregiver mortality. Schulz and Beach used a questionnaire to measure strain, asking participants to rate statements as no strain, some strain, or a lot of strain, to capture levels of caregiving demand. After adjusting for socioeconomic and health factors of those providing care, they found that informal caregivers experienced a 63% higher mortality as compared to non-caregivers, suggesting that caregiving strain is an independent risk factor for mortality among elderly caregivers living with the care recipient. Schulz and Beach did not correlate

self-reported strain with any other measure (e.g., increased assistance with ADLs or biomarkers) or account for individual differences. There also was no suggestion of any possibility of benefit from caregiving. Investigations of the burden of the caregiver experience have also looked at objective factors and outcomes related to the subjective experience. Vitaliano, Zhang, and Scanlon (2003) conducted a meta-analysis of 23 studies, comparing physical health of caregivers with age- and sex-matched non-caregivers. Vitaliano et al. considered two primary mechanisms for adverse health impact. The first mechanism was the activation of stress hormones via the hypothalamic-pituitary-adrenal axis and the sympathetic adrenomedullary axis. The second mechanism was distress itself, which can trigger detrimental health behaviors such as poor diet choices, sedentary behavior, and alcohol and other substance abuse. Results of the meta-analysis were consistent with statistically significant, weak adverse effects of caregiving on stress hormones, antibodies, and self-reported global health.

Von Känel et al. (2010) used coagulation markers as an indication of allostatic load, associating behavioral problems of the PWD with clotting problems in the caregiver. Von Känel et al. (2011) found that cardiometabolic risk factors are higher in spousal caregivers of patients with AD and decrease with patient institutionalization or death. In contrast, Clark, Bond and Hecker (2007) found that allostatic load actually continued to rise in caregivers after they had relinquished care either by death of their spouse (9/44) or admission to residential care (35/44).

Caregiver age, gender (Almberg, Jansson, Grafstrom, & Winblad, 1997; Annerstedt et al., 2000), relationship (Zarit, Todd, & Zarit, 1986), and socioeconomic factors (Andren & Elmstahl, 2007) have been studied and found at least modestly associated with caregiver

burden. However, Vitaliano et al. found only slightly greater risk among the caregivers with higher risk (9%) when considering stress hormones, antibodies, and global health. Sex (male) particularly figured as a moderator of the relationship between caregiving and poor health, but the authors were unable to establish whether an actual difference in health existed between men and women as opposed to subjective sense or higher health awareness because of the measures used.

The caregiver's gender, socioeconomic status, or a history of the patient's previous institutionalization didn't influence caregiver burden in a study (Annerstedt et al., 2000) looking at why and when caregivers decide to institutionalize their charge, and neither did functional or cognitive status as measured by ADL performance and formal mental status exam. The caregiver's *opinion* of their charge's social dependence and their own disappointment significantly correlated with measures of burden. Thus the same facts of the situation are appraised differently. Both an impaired sense of caregiver identity and nocturnal deterioration of the patient—either behaviors or simply wandering about at night, so that constant vigilance was required—also contributed to feelings of having reached the limits of their caregiving ability.

Behavioral and psychological symptoms of dementia are considered among the most difficult stressors faced by caregivers (Woodhead, Zarit, Braungart, Rovine, & Femia, 2005; Yaffe et al., 2002), but there is a chicken and egg aspect to this as shown by studies (Perren, Schmid, Herrmann, & Wettstein, 2007; Sink, Covinsky, Barnes, Newcomer, & Yaffe, 2006) that found that caregiver characteristics (such as avoidance and anxiety) are associated with increased behavioral and psychological disturbances of the person with dementia.

Other caregiver attributes, including strength of character and empathy, have been studied with regard to perceived stress. Harmell et al. (2011) reviewed 11 non-experimental studies of resilience factors (e.g., personal mastery, self-efficacy, and coping style) among dementia caregivers. They concluded that these resilience factors moderated physiological markers of the stress response, adding to the viewpoint that it is not the facts of the caregiving situation per se, but the caregiver's appraisal of meaning that leads to the sense of burden. When a caregiver's concern is focused on the feelings and response of the cared for, the appraisal of the situation changes. Harris et al. (2011) developed an "exemplary care" (EC) scale in which caregivers rated the frequency (*never, sometimes, often, and always*) of 11 statements (e.g., *I make sure the food [name of care receiver (CR)] likes is available for meals and snacks. I take the time to sit and talk with [name of CR]; To make [name of CR] feel refreshed and good about him/herself, I do things like being sure he/she is dressed nicely or that his/her hair is clean and styled.*). The statements generally probe for empathetic engagement in the provision of care. Harmell et al. found that those scoring higher on the EC scale also scored lower on measures of burden and subjective appraisal of behavioral problems. The perception of providing exemplary care significantly correlated with decreased feelings of burden.

Gonyea, O'Connor, Carruth, and Boyle (2005) studied "feeling good from doing good." They studied 56 spouses and 24 adult children providing care to PWDs, investigating the relationship of burden to self-reported self-efficacy and depression. They found a significant, positive correlation between burden and self-reported depressive symptoms and negative correlations between burden and self-efficacy. Certain personal factors clearly affect the way we represent experience. How we ask the question also influences what we

find. Butcher, Holkup, and Buckwalter (2001) studied the experience of family dementia caregiving, finding that despite sadness, stress and frustration, most caregivers (78%) found positive aspects of meaning and personal growth from their experience. This was a phenomenological analysis of 103 previously collected interviews in which caregivers were asked to describe what it was like caring for a family member with dementia at home. Liew et al. (2010) identified three factors significantly associated with a sense of personal gains from caring: mental well-being of the caregiver, use of active management as a caregiving strategy, and participation in caregiver educational and support group programs (adjusted R^2 32.3%).

Netto, Jenny, and Philip (2009), using grounded theory methodology in a Singapore study, found that all participants (10 women and 2 men) reported having gained from being the primary caregiver of a family member with dementia. These gains included personal growth—becoming more patient, understanding, stronger, and more resilient. The participants also reported improved relationships with the cared-for relative, other family members, and older people in general. “Higher level gains” were reported by most of the participants. These included a sense of greater connectedness to *God*, or something beyond (higher power), as well as existential satisfaction—finding meaning or purpose in caregiving.

Active helping has been associated with greater caregiver well-being (Poulin et al., 2010) and more so in relationships perceived as interdependent or “enmeshed” (p. 6). Love, empathy and positive appraisals can affect caregiver well-being, independent of the care recipient’s health status and functional impairment, even under stressful situations. However, no definition of empathy was offered in this study (Poulin et al., 2010).

Caregivers can experience burden and satisfaction at the same time. Andrén and Elmståhl (2005) investigated influences associated with satisfaction among 153 family caregivers of PWD using a caregiver's satisfaction scale, a burden scale, as well as the Sense of Coherence (SOC) scale developed by Antonovsky (1993, as cited in Andrén and Elmståhl, 2005). Caregivers expressing high levels of satisfaction valued their relative through a sense of mutuality (i.e., a sense that their relative would respond the same if the situation was reversed), finding purpose and pleasure in helping them challenge difficulties. Gender, total burden, and subjective sense of health did not influence satisfaction. Higher SOC was associated with less sense of burden and greater subjective health.

Antonovsky's (1987) salutogenic model proposes that the way people view life influences their health to the point some people will remain healthy under large amounts of stress while others can tolerate stress minimally. This life view involves both comprehension of the situation, management of resources and meaningfulness. SOC is not static; instead it develops over the life span (Erickson & Lindstrom, 2006).

Välimäki, Vehviläinen-Julkunen, Pietilä, and Pirttilä (2009) investigated dementia caregiver depression in a study of 107 female and 66 male spouses of PWD. They examined factors leading to increased sense of coherence (SOC) and health-related quality of life (HRQoL). Male caregivers reported less depression and scored higher on Antonovsky's SOC scale, although no significant difference was found in HRQoL. The authors conducted an exploratory factor analysis of the SOC items and found five factors they labeled *consistency of life, contentment, purpose, disappointments, and interest in life* that accounted for approximately 47% of item variance, with consistency of life accounting for the most (~27%). This factor comprised items pertaining to caregivers' capacity for comprehending

life experiences as structured and orderly, either reinforcing a sense of coherence or intensifying disconnection.

Sanders, Ott, Kelber, and Noonan (2008) specifically studied the lived experience of 201 caregivers who scored high on a caregiver grief inventory, speculating that the pattern and intensity of grieving has strong implications regarding burden, depression, and stress. Of the caregivers, 44 were identified as experiencing high grief, a sense of isolation, restricted freedom, life stressors, and systemic issues (procuring resources) that the other caregivers did not.

How one comes to represent the experience of caring for a spouse with dementia is not clear. In addition to SOC, other mediating factors have been studied, including secure attachment styles (Cooper, Owens, Katona, & Livingston, 2008), emotion-focused coping strategies (Cooper, Katona, Orrel, & Livingston, 2008), and resilience (Harris, 2008) that bring about an improved sense of self and personal growth. Yap et al. (2010) developed a rating scale of 1–5 (representing agreement with statements: Disagree a lot, Disagree a little, Neither agree nor disagree, Agree a little, Agree a lot) to measure sense of personal and relationship improvement as a result of informal family care giving. Of the 238 surveyed, more than 50% reported agreeing a little or a lot with 10 indices of self-acceptance, meaning, or closure type of gain as a result of caring for a relative with dementia (37.4, 41.2% [agreement of a little/ a lot] for deeper insight into the meaning of life; 24.4, 36.15 [a little/ a lot] for growing spiritually and 37.8 and 23.5 [a little/ a lot] for being inspired towards altruistic goals). Salmon et al. (2005) in a correlation study of hospice caregivers found that higher scores of self-acceptance, finding meaning and closure, and caregiving comfort were associated with caregiver's sense of reported gain; they also found that caregiver comfort

with caregiving and the personal sense of meaning mediated feelings of burden. Higher burden was associated with being female, poorer health, higher education and amount of help required for ADLs. Whether considering meaning making or sense of coherence, a preliminary factor is appraisal. How one comes to a conclusion that some life experience is a burden, benefit, opportunity impacts health, health behavior as well as caregiving. It is an important component of process studies of caregiving/ care receiving but is understudied.

Men as Caregivers

Välimäki et al. (2009), Andrén and Elmståhl (2005), and Yap et al. (2010) found decreased SOC, worse QoL, and greater depressive symptoms among female caregivers. Thompson et al. (2004) found sex differences in emotional and biological responses of spousal caregivers. Although there was no difference in social support or resources, male spousal caregivers had significantly lower levels of stress, depression, caregiver burden, anxiety, anger-hostility, and somatic symptoms, and higher levels of mental health, sense of coherence, NK (natural killer) cell number, and social and physical functioning than female caregivers. Women caregivers report more psychiatric symptoms: depression, anxiety, and lower life satisfaction (Croog et al., 2006; Yee & Schulz, 2000).

The gender discrepancy identified between male and female spousal caregivers has been explained in different ways. Male caregivers are more likely to get informal help with caregiving, and engage in preventative health behaviors and report higher mastery (Yee & Schulz, 2000) suggesting a fundamentally different style to caregiving. Collins and Jones (1997) found that the increased strain women experienced was related to a higher expectation of women as generally better suited to the caregiving role. Wives, therefore, felt a greater obligation to care. The authors concluded that social factors are the chief determinants of

wives' higher levels of strain and distress. Kirsi, Hervonen, and Jylhä (2004) also found a social constructivist influence on male responses when comparing written texts elicited by a formal letter signed by a male physician and interviews conducted by women of Finnish men caring for their demented wives, concluding that methods of data collection can affect data, and that there are stereotypical narratives current in social discourse that are used when we answer questions. The role of traditional belief systems about gender may impact the self-reporting of burden because it may seem to imply weakness and loss of control (Baker, Robertson & Connely, 2010; Kaye & Applegate, 1993). This gendered stereotyping has also been found with regard to recognition of dementia symptoms and disclosure of a dementia diagnosis to family or social others. Women typically are the first to notice a change in their husbands, reporting an “identifying moment”—a stark recognition of dementia compared to men who tended to rationalize their wives’ behavior until concerns of others forced awareness (Hayes, Zimmerman, & Boylstein, 2010). These authors conducted a qualitative study involving intensive interviews with 13 caregiver husbands and 15 caregiver wives. They found diagnosis of dementia was associated with an affirmation of a husband’s identity as protector and provider adding status, whereas women are more likely to experience a status loss, which resulted in the women’s delay in accessing services. Holst and Edberg (2011) studied the impact of dementia caregiving over a three-year period—both the “state of mind” of people with dementia and the burden or satisfaction of the caregiver. Thirty-two couples were interviewed: 24 were spouses, 21 were couples where women cared for men, and eight of the caregivers did not live with the care receiver. Both caregiver burden and satisfaction were dichotomized as yes/no for the purpose of regression analysis. Women reported significantly more burden at baseline and at 2 years ($p = .009$). Men reported more

satisfaction from caregiving at 1 and 3 years. Though previous studies have shown that burden and benefit can be felt simultaneously (Andren & Elmstahl, 2005), Holst and Edberg did not examine this in their study. However, there may be a qualitative difference between men and women in the appraisal of one's spouse's cognitive changes in developing dementia.

Gender identity, differing views of masculinity, and personal power are emerging as focuses in the studies of elderly husbands caring for wives with dementia. Russell (2001, 2007) describes elderly men as mistakenly stereotyped as a "...genderless, homogenous collective group whose value and sense of being needed has diminished rather than a diverse group of individuals who continue to grow and transform" (2001, p. 352). Russell's (2001) study involved in-depth interviews with 14 elderly men (ages 68–90), asking how they came to decide on caregiving, what exactly they do, and how they feel about it. These men expressed commitment and devotion as the meaning of their experience, though they often felt isolated and invisible as a result. They were able to tackle the caregiving task through management skills they had developed professionally through previous employment. The men expressed amazement at what they had taken for granted, "... she always made it look so easy" (Russell, 2001, p. 359), discovering the complexity of their wives' home management skills as they took on the tasks their wives had shouldered in the relationship, resulting in a retroactive respect and a sense of reciprocity in their current role. The meaning of caregiving was expressed as changing their outlook, becoming more compassionate, and achieving higher self-esteem.

Calasanti and King (2007) conducted a qualitative study of spousal caregivers of home cared PWD with the purpose of determining if gendered patterns of caregiving would be demonstrated and how these gender ideals influence stress and coping. Twenty-two

caregivers (9 men and 13 women) were interviewed. The women saw their care-giving roles as a continuing process of their care work, but the men approached care giving as they would a new job. “At first... when you start taking care of a woman...you don’t know exactly how to do it...You just have to pick it up like you do a trade” (p. 520). When the caregiver wives were confronted with their husbands’ non-compliance, they tended to lie or use manipulation tactics, whereas the men used stern voices to intimidate or physical force to get their wives to comply. “I tie a leash on her ankle and mine so that I know when she is getting up. Otherwise she will pee anywhere in the house” (p. 522). Calasanti and King arrived at five patterns of male coping response to stress and feelings. The men tended to break caregiving into particular tasks that they remained focused on until completion. They were more successful at blocking emotion than the women. They were able to minimize the disruption of caregiving and changes in their life by continuing with pre morbid routines (e.g., finding sitters so they could go fishing). They were able to find distraction in hobbies. When these four strategies were insufficient, the men also tended to self-medicate more than the women. These patterns are stereotypical of men in this age group, 66–83, and although they are consistent with Russell’s studies (2001, 2007) a change to the then prevailing stereotype of women as nurturers and men as providers may change the social construction of behavior norms with a resultant change in patterns of behavior.

Black, Schwartz, Caruso, and Hannum (2008) studied caregiving by older men within the context of suffering in later life. They found that multiple losses, including the threatened loss of an integrated existence, contribute to suffering as older men take on the traditionally feminine role of care giving while holding on to masculine attitudes and behaviors in reaction to emotions, expressions, and decreasing reliance on each other, as their

wives became more debilitated. Their research produced four in-depth interviews from which three themes were derived. The first theme was the “power of the little,” the way small details in the process of day-to-day caregiving can become a catalyst to hope or change or resignation. The following is a particularly poignant example (p. 183):

When I put her (wife) to bed, I said, “Give me a foot, put it up on me, I’ll take your shoe off. But if you get my knee dirty, you’re going to wash my leg.” She says, “It would be an honor.” And she came out with it so plain, so sincere you know. She said, “It would be an honor.” I said, “Good Lord.” That was just like socking me in the stomach. And she really meant it, the way she said it.

The second theme was self-identity and marriage-identity preservation. This came from the sense of self-esteem the husbands gained through succeeding in the role of caregiver, which integrated insight and empathy, developed in later life. As their wives grew more demented the husbands described their developing sense of their spouses’ subjectivity—the ability to know what they were feeling or thinking about circumstances. The third theme that emerged through the data was finding purpose in care giving. Not only did care-giving not impede existential tasks, but it also provided a platform from which to view their entire life up to the point of interview and view it from the standpoint of compassion, perseverance, and having done the right thing morally (cf. Brown, Chen, Mitchell, & Province, 2007, p. 357, “...people that put their family away and don’t take care of them miss everything.... It’s just a privilege to take care of her.”). The third theme was finding purpose in the role of caregiving. Husbands reported finding caregiving symbolic of their love and commitment to their wives and lead them to believe their own longevity had the purpose of enabling them to remain caregivers until their wives death.

Ducharme et al. (2007) also studied relational aspects of male care giving. As the marriage relationship transforms with increasing debility related to wives' dementia, husbands received more emotional support than physical assistance with care from other family members, and almost all were receiving formal care and social services. In addition, contacts with friends diminished, since maintaining social connections had largely been the role of the wives. Husbands provided instrumental (providing and protecting) as well as personal care, and tended to minimize their needs for help. The changing relationship was especially stressful but was balanced by perceived positive aspects of caring, although this gradually diminished with increasing cognitive impairment and relational deprivation.

Through these studies comes the understanding that care giving becomes an opportunity to find personal meaning in the compassion and competence required in caring for another, and this has moderating effects on the psychological and physiological stress of physically caring for the needs of family members with diminishing ability to care for themselves. Husbands who can transform their roles of provider and protector from that of the stereotypical breadwinner to that of a protector of self-esteem, dignity and personhood and a provider of personal care and social experience (Sanders & Powers, 2009) find what one participant called a "pastor's heart" (p. 48). "You need to have a concern, not for yourself but for the one you're doing the caregiving for and other people. It don't develop overnight" (p. 48). How caregiver husbands experience their wife's dementia and how they interact with their wives to develop this appraisal has not been studied.

Although memoirs do not capture the immediate consciousness of dementia from the perspective of caring spouses, they do give some insight into strategies used to manage the daily struggle. John Bayley (1999) writes about his wife Iris' dementia in a popular press

memoir. Iris Murdoch, a philosopher and novelist, is writing her last novel in part of his memoir. He demonstrates her developing confusion by quoting her as she speaks of her main character "I can't make out who he is or what he is doing," (p.213). A critic of the novel, Leithauser (1996), without knowing of Murdoch's dementia, wrote "Could even Murdoch's staunchest admirers explain why the phrase "then suddenly" should appear three times in a single paragraph? Murdoch scatters her pet words like so many nails in the reader's road, often gluing them into shrapnel-like clusters: "slowly now," "suddenly then," "now of course," "there was then" (P10). In retrospect, this evidences her contracting facility for language and a phenomenology of grammatical deterioration. Bayley's sense of loss as he describes watching his educated, formerly erudite wife becoming enthralled by the children's television show *Teletubbies* also ventures into the in-between of ambiguity because it is a place of solace for both of them as he grieves in his comparisons between who she was and who she is. During the broadcast, she is engaged, and he is relieved from the process of managing her cognitive deficits.

Suchet (2010) and Petersen (2010), both journalists caring for wives with early onset dementia, wrote memoirs of the caregiving experience. Both memoirs follow a theme of "soul mate" love found and slowly lost to the ravages of cognitive impairment. These are the "first met" scenes that establish the unity of the couple. Peterson (2010, p. 23) calls it "darling and darling." Although the initial and immediate awareness of dementia is not available, one can follow the permutations of interpretation from the early clues that Petersen realized, in hindsight, through the attempts at preserving his wife's personhood and his use of the Alzheimer's Association resources to create a social construct of meaning for the experience. There are aspects of the considered and reviewed or reflected versions that get to

the primal sense of the lived experience—“The thing itself may have been there always, moving subterraneously along the nerves, choosing hesitantly, forgetting, before acknowledging its medical name” (Alterra, 1999, p. 3.)—and those that do not.

However, memoirs are, in general, selective and edited views that may mask ulterior motives. For example, in a critique of *Elegy for Iris*, Wilson (2003) writes, “John Bayley had an axe to grind: in the shadow as a writer and critic for years, cuckolded constantly, stuttering and satirized by colleagues, John Bayley took his revenge by writing the books about life with his wife” (p. 7). In my research I want to get to the caregiving experience itself, before and as it is reflected upon and interpreted within the current social context.

The Care Recipient’s Perspective

Authors including Kitwood (1997) and Whitlatch (2001) promoted inclusion of the perspective of those with dementia in the study of dementia caregiving. It becomes increasingly clear through these studies of what it is like to have dementia that there is an ongoing negotiation with its social context in our society, what Goffman (1963) described as “management of spoiled identity,” in the title of his book and Kitwood (1997) called “malignant social psychology” (p. 45).

Beard and Fox (2008) conducted an ethnographic study of the impact of a dementia diagnosis, mild cognitive impairment or early stage Alzheimer’s disease. Their findings suggest an ongoing process of managing a sense of a competent self; maintaining personhood becomes increasingly difficult because the constructs available for explanation via medical clinics or the Alzheimer’s association are dependent on biomedicine. Respondents described a process of learning to be demented. Those who attended support groups were able to derive a sense of identity that challenged the prevailing construct of “Alzheimer’s victim.”

The pervasiveness of the medical construct is illustrated by an anecdote in Christine Bryden's memoir (2005). She embarked on a lecture tour several years after her diagnosis, talking about living with early onset Alzheimer's. Physicians in the audience criticized her for claiming to have dementia without evidence, yet when she included her personal CT scans in her presentation some claimed that she could not be speaking the way she was if those were indeed her CT scans.

Bryden (2005) and McGowin (1993) are both women who have written chronicles of their lives since being diagnosed with dementia. They describe the process of managing identity, which the former compares to a dance and the latter to a labyrinth. Both women describe a deepening intimacy in their changing relationships with their partners, as the husbands took on the role of managing their memories and keeping track of temporal details.

In Gillies' (2000) study, as well as Langdon, Eagle, and Warner (2007), many respondents did not acknowledge dementia or Alzheimer's disease, preferring to talk about memory loss or forgetfulness as part of the normal aging process, and preferring to be considered old and not diseased. Many studies of the lived experience of dementia emphasize the role of previous personal identity and self-concept on coping responses and meaning making. Clare (2002) describes coping responses on a continuum from self-preserving to integrating hope and despair to acceptance of a new self-identity. Clare (2003) conducted a phenomenological study looking at awareness in early stage dementia, finding a central dynamic at play expressed through an iterative processing of registering, reacting, explaining, experiencing and adjusting to threats to self-maintenance. Responses reflected attempts to minimize or normalize perceived deficits in awareness as they surfaced until that was no longer possible without a restructuring of the sense of self. Clare conceptualizes this

as a process shaped by pre-existing coping and social interaction styles. Retreating from social activities is a common response, as are shame and hiding of the initial diagnosis. For example, McGowin (1993) had a blepharoplasty, because “If I looked younger outside, my inside might be fooled” (p 65).

Clare, Goatner, and Woods (2006) explored the role of illness representations in a self-regulation theory of adjustment in a study of 22 participants with mild to moderate dementia. Through semi-structured interviews, the participants were asked for examples of incidents in which they sought medical intervention for changes they experienced related to their diagnosis and their explanations or representation of the incident. Most participants saw their situation as an aging problem, not an illness, but nonetheless expressed feelings of frustration, anger, self-blame, isolation, embarrassment and uselessness.

Harris (2006) looked at the experience of dementia among older adults living alone, all of whom were concerned about potential impact of progressive cognitive loss and expressed wishes to maintain autonomy, independence, and a continued sense of accomplishment through meaningful activities. Phinney, Chaudury, and O’Connor (2007) found that household chores and social interaction with others with dementia were important activities for participants, because these activities represented continued autonomous enjoyment of life, supporting their identities and connectedness as opposed to isolation.

Even though PWDs often demonstrate difficulties with concentration/easy distractibility, and misunderstanding questions (Cotrell & Schulz, 1993), a sense of self has been demonstrated even with severe dementia (Clare, Rowlands, Bruce, Surr, & Downs, 2008; Mahew, Acton, Yauk, & Hopkins, 2001; Sabat & Harre, 1992), which means that self-

expression, assertion of will, sense of humor, emotional expression and social sensitivity remain intact long after difficulty finding words and memory are impaired.

Sabat (2005) describes the individual with Alzheimer's type dementia as a "semiotic subject" (p.1030) by which he means they meet three requirements: 1) Acting with purpose 2) Have an intact interpretive scheme 3) Ability to evaluate based on the interpretive scheme. Using these criteria and two case studies he demonstrates the importance of studying discourse in order to appreciate the extent of meaning making in those with dementia. PWDs scoring low on tests assessing ability to recall words after five minutes or ability to subtract serial sevens still have the ability to feel shame and pride as well as concern for the well-being of others. This is important in terms of understanding difficult behaviors manifested by PWDs. The PWD's crying out or aggression would be seen differently, considering their awareness of their own deficits, the negative social connotations of those deficits and the resulting shame and humiliation. Instead of behavior being seen as the result of neuropathological injury, it would be seen as communication of frustration. This is consistent with the work of McLean (2007), and Bourbonnais and Ducharme (2010), who concluded through ethnographic study that the common behavior of screaming in those with moderate-to-severe dementia is the language of frustration and suffering influenced by the surrounding behaviors of patients, family members, and care-giving staff in nursing homes.

In their personal chronicles of dementia, McGowin (1993) and Bryden (2005) talk about an early awareness that there were incidents when their brain seemed disconnected from their purposeful movement resulting in spilling drinks or tripping. Bryden describes the way routine tasks become harder requiring more thought. The fluidity of transition disappears as she loses the connectivity, stuck because she needs to focus on one thing at a

time. Phenomenologically, one can almost feel the shrinking of background context and the sluggishness of consciousness. She describes problems with vision, balance, and direction. “I am anxious, as I seem to be less and less able to capture and communicate these thoughts” (p. 101). She becomes more linear and attentive to sequence, step-by-step, as the ordinary develops complexity. Deciding what to wear requires too much energy. She loses track of where she is in a recipe. She has to write down and cross off every step of routine chores. She needs to watch where she puts her feet as she walks. “The world feels like a wobbly place, and it is hard to know where each part of me is in space, (p. 103). Falls are common, fluids spill easily from glasses, and there is an undercurrent of anxiety as she feels she should be doing something, but not remembering what.

These memoirs offer excellent insight to the experience; yet, there is the question of accuracy. For example, McGowin (1993) uses a detailed timeline of events that includes action errors and memory lapses from the viewpoint of an omniscient narrator who uses direct quotes (i.e., from the neurologist, “You know Diane, I really think it is time you ceased trying to work,” he said gently as I paused for breath. “I am recommending that you retire.” “... No,” I stated emphatically. “I still have ‘many miles to go before I sleep,’ Dr. T., see? I remember that, I even remember who wrote it! Robert Frost! See?” (p. 42). Because these are stories edited for emotional impact, the detail of the quotes is potentially unreliable.

Even mild cognitive impairment has been associated with decreases in physical mobility and distance traveled alone from home (Buchman, Boyle, Leurgans, Barnes, & Bennett, 2011; O’ Connor, Edwards, Wadley, & Crowe, 2010), and falls (Liu-Ambrose, Ashe, Graf, Beattie, & Khan, 2008). In this way, a constricting area of comfort balances the emotional constriction; routine and predictability provide safety from the various threats to

self and personhood. Problems with gait and postural sway have been found in women with even mild cognitive impairment.

Focus on the Caregiver/Care Receiver as a Couple

Wright (1991) studied perceptions of the strength of the marital relationship among caregiving spouses and their partners as compared to a comparison group. They found a discordance in self-reported relationship quality between carers (less quality) and the cared for (more quality).

Davies and Gregory (2007) looked at marriage biography, advancing the theory that through eliciting a marriage biography, identifying the shared memories, stories, and events that have merged into a dyadic meaning and given purpose to their lives, we have a way to understand their developed meaning and quality of life. This is an understudied area, though multiple authors point to the importance of contextualizing a collaborative production of meaning. The quality of the pre-morbid relationship of caregiver and spouse is associated with more positive and less negative aspects of care giving (Lewis, Hepburn, Nyan, & Kirk, 2005).

Keady and Nolan (2003) found four patterns of spousal relationship dynamic in dementia caregiving: working alone (early in the process when the PWD may be hiding symptoms) working separately (parallel behaviors where the PWD continues to try and hide symptoms while the spouse becomes more vigilant with suspicion), working together (through disclosure and discussion the couple works together to make the most of the situation), and working apart (as a result of prior relationship difficulties or advancing cognitive deficit, there is no longer a shared purpose).

In a single-case study design, Hellstrom, Nolan, and Lundh (2005) describe one couple living together. After 52 years of marriage, a widower married a woman who had never been married; both had been members of the same church for 60 years. Her diagnosis came 4 years after their marriage and according to both, reinforced the sense of meaning in their relationship and marriage—she could not live alone without difficulty and he had the ability to help her. At the point of the interview, the husband felt they had a reciprocal caring and companionable relationship.

In a later grounded-theory study, Hellstrom, Nolan, and Lundh (2007) explored the ways in which PWDs (eight women, twelve men) and their spouses responded to dementia over time by interviewing the 20 couples over 5 years. They found that caregivers, by imagining the attitude of the spouse, were able to maintain a “nurturative relational context” and maintain balance by doing things together, emphasizing the importance of couplehood and interdependence. The data reflected three patterns of management: sustaining couplehood, maintaining involvement, and moving on. “Moving on,” occurred toward the end of the study when caregivers felt increasingly alone and their spouses had become more passive.

Many authors (i.e., Braun et al., 2009; Cotrell & Schulz, 1993; Clare, 2002) have stated the need for more dyadic studies because the nature of couplehood within the dementia–caregiving relationship is poorly understood and requires a more integrated approach. As Eisikovits and Koren (2010) point out in a study of couplehood in old age, “The dyadic version is more than the sum of two individual versions” (p. 1645).

Systems approaches. Pearlin, Mullan, Semple, and Skaff (1990) proposed that caregiver stress is the result of a dynamic process of interactions between socioeconomic

characteristics and resources: mastery, caregiver competence, management of meaning, management of situation, management of distress, role captivity, relational deprivation and loss of self.

Lewis, Hepburn, Narayan, and Kirk (2005) describe four patterns of caregiving among a sample of 132 spouses:

- Relational Experience—centers on the continued bond in the context of their lives together.
- Instrumental—focuses is on tasks related to the additional work and the discourse is self-centered on the impact and burden on the caregiver.
- Reactive—spouses respond to changes related to dementia, provoking frustration and anger, yet still with respect to their changing relationship.
- Role Acquiring—describes relationships in terms of the changing role and new skills (reflecting expansion of self) in response to the dementia, often expressing pride and satisfaction.

The study examined these patterns further, using quantitative measures of response and outcome of caregiving. Relational spouses scored higher on caregiving competence and management of meaning and lower on burden scales. Role acquiring was the only one of the four patterns in which significant gender differences were observed and identified only in women. A limitation of the study was that Lewis et al. did not include data from 41 participants (31%) who did not fit any of the patterns.

Finding meaning in caregiving is a process. Farran, Keane-Hagerty, Salloway, Kupfer, and Wilken (1991) and Farran, Miller, Kaufman, Donner, and Fogg (1999), and McLennon, Haberman, and Rice, found that spouses who found meaning in caregiving had

lower burden scores and higher general health scores. The *Finding Meaning Through Caregiving* instrument (Farran et al., 1999) was developed from a qualitative study of 94 family caregivers of PWD (34% wives, 32% husbands) who participated in a 2-hour structured interview. The interview included seven open-ended questions about life changes resulting from caregiving, benefits, regrets, and difficulties. The data analysis revealed four major themes in the responses:

- Loss and powerlessness
- Values, choices, provisional and ultimate meaning
- Resources
- Responsibilities of caregiving

From the four major themes, six existential themes were identified:

- Acknowledging present loss
- Acknowledging powerlessness
- Personal choices
- Positive aspects
- Provisional meaning
- Ultimate meaning

Subcategories also were determined for each of the existential themes (e.g., “choosing a positive outlook” or “drawing upon personal fortitude” are subcategories for personal choices). Following this analysis, the researchers undertook a quantitative analysis to measure the percentage of participants who responded positively to the subcategories, and then conducted correlation analysis with measures collected as part of a larger longitudinal

study of dementia. Caregivers who reported higher burden also reported greater powerlessness and lower levels of personal choice.

Victor Frankl (2000, 2006) held that self-transcendence is the driving factor in human being—not pleasure or homeostasis. Frankl defined self-transcendence as the desire to find and fulfill a meaning in life. His early theorizing was intensified through his experience in a Nazi concentration camp, where he saw prisoners' inner strength develop in response to aiming at a future goal, but also saw defeat when no future was seen. Frankl thought that we have the freedom to act, and that what we imagine we have coming to us or are entitled to in our expectations was less important than what human life requires of us, which is right action and right conduct. "Life ultimately means taking the responsibility to find the right answer to its problems and to fulfill the tasks it constantly sets for each individual" (Frankl, 2006, p. 77). Realization of one's full human potential depends on the extent to which we change the focus from ourselves, be it through serving a higher cause or loving another person. This self-transcendence is what Frankl considers the essence of human existence. Choice and freedom are fundamental.

Brown, Chen, Mitchell, and Province (2007) studied the help-seeking process of older husbands caring for wives with dementia, using Newman's theory of "health as expanding consciousness" as a conceptual framework. Like Frankl, Newman proposes that true freedom (and health) results from moving focus from the self. These researchers describe the opportunity to choose informal caregiving as a choice point precipitating expanded consciousness and improving health. Michael, one of the participants, said, "I'll have to say this: people who put their family away and don't take care of them miss everything. If they

can, they'd get so much more 'cause they're missing so much" (p. 357). This also echoes Frankl's themes.

In support of this eudaimonistic view of health as going beyond physiologic processes to engagement in the our well-being, Brown, Brown, Schiavone, and Smith (2007) developed a physiologic explanation, Selective Investment Theory (SIT), in response to work done (i.e., Brown & Brown, 2006; Brown, House et al., 2006). These researchers found a functionally beneficial relationship between helping others and decreased depression, stress, and mortality suggesting an evolutionary, survival of the fittest aspect. Brown et al. (2009) conducted a national longitudinal survey to discriminate effects of long-term proximity to the illness of a loved one to the actual caregiving. Their results found a statistical correlation ($p = .012$) between providing at least 14 hours of care per week to someone with serious illness and decreased mortality, suggesting that helping is protective (in contrast to above-cited studies such as Annerstedt et al. (2000), suggesting greater amount of time spent caring predicted greater burden.

The nature of choice in human existence is important to this research because it bears on lived experience. Merleau-Ponty writes about "the existential project, which is the polarization of a life towards a goal which is both determinate and indeterminate..." (p.518). Ambiguity of this nature is an ongoing thread in phenomenology, which seeks to understand the present lived experience against the backdrop of the essence of that experience over time, history and circumstance. We breathe in the world and exhale it a little differently.

Carbonneau, Caron, and Desrosiers (2010) developed a conceptual model of positive caregiving experiences based on an integrative literature review that was not limited to family caregiving in dementia. Carbonneau et al. categorized domains of positive aspects:

quality of caregiver/care receiver relationship, feeling of accomplishment, and meaning of the role in daily life. The quest for meaning is a recurrent theme in the literature on benefits of caregiving, but is not clearly defined. In developing their framework, they point out “...meaning becomes part of daily life and depends on the caregiver’s ability to make personal choices, to focus on positive events, and to find meaning in daily experience” (Farran et al., 1991, as cited by Carbonneau et al., 2010, p. 336). According to Carbonneau et al., global meaning is the result of integrating values and philosophical and spiritual beliefs. The positive outcome is conceived as determined by the effects of the caregiver’s sense of self-efficacy and enrichment through joyful, satisfying daily events on the domains of relationship quality, caregiver’s feeling of accomplishment and caregiver’s sense of everyday meaning.

This model seems to overlook the complexity of meaning making. “My life is crap,” is a possible meaning for the caregiving experience that conceivably results from the integration of values with spiritual and philosophical beliefs. This is not the kind of meaning my research is intending, because the focus in phenomenology is more on the essence and meanings of experiences as given, prior to such integration with pre-existing beliefs. Understanding how phenomena as experienced are appraised and given meaning is essential.

In contrast with the model of Carbonneau et al. (2010), Piiparinen and Whitlach (2011) developed a model that suggests a caregiver’s burden is not the result of the tasks of responding to developing deficits in their spouse’s self-care as much as it is a struggle with loss and isolation. They consider “existential loss” to be the psychological state of carers who encounter the multiple losses as their partner declines and their own lives become significantly changed in focus. The model situates dyadic well-being at the center. Dyadic

well-being is conceptualized as being affected by the caregiver's ability to integrate loss in a context in which dementia is stigmatized and viewed primarily from a biomedical viewpoint. The ability to integrate loss through empathy results from an interplay of what is described as *deep mind* and *surface mind* (p. 189), in the development of appraisals and assignment of meaning. The surface mind is conceptualized as self-focused, characterized by conscious rational thought and situational control. The deep mind is the intuitive, symbolic shared sense of humanity as well as the location of "...repressed pain and unresolved psychic conflicts.... It exists beyond the limits of the ego, subsumed instead by something immortal" (p. 189). In this way, Piiparen and Whitlatch (2011) address the question of what differentiates those who gain from their experience and those who mostly feel distress.

The process suggested is the caregivers and receivers begin as individuals, but exist within the dyadic relationship that is challenged by awareness of the advancing dementia. This presents the existential moment of choice. The divided deep mind/surface mind is influenced by past relationship attachment styles, as well as the current social context of dementia in development. Outcome in this model is portrayed as resulting in dyadic equality and well-being via coping based on empathy, open communication and negotiated decision-making or diminished well-being and dyadic inequality with coping based on paternalistic authoritarian decision making.

This a very good systematic approach to the question of gain versus distress, but the inner workings represented by the large shaded oval in Figure 2.1 representing tension between the deep mind and the surface mind can be more adequately depicted, from a phenomenological perspective, as consciousness of dementia. How we cope or do not, whether we get sick from caregiving, or decide to institutionalize our PWD all cascade from

the central “givenness” of dementia within the lives of the carers and cared for. This is what Husserl called the *thetic* character of an act of consciousness. This includes judgment, perception, imagination, and the modifications that lead to arrival at a position. Though there are many studies that have looked at the “experience” of dementia caring and caregiving, they usually have occurred after the perception, judgments, and interpretive / integrative modifications have taken place. In contrast, I wanted to explore the many aspects of givenness to better understand dementia through the empathic-lived experience. I am looking for the pure intending before the adjustment to the surrounding life-world’s current perspective.

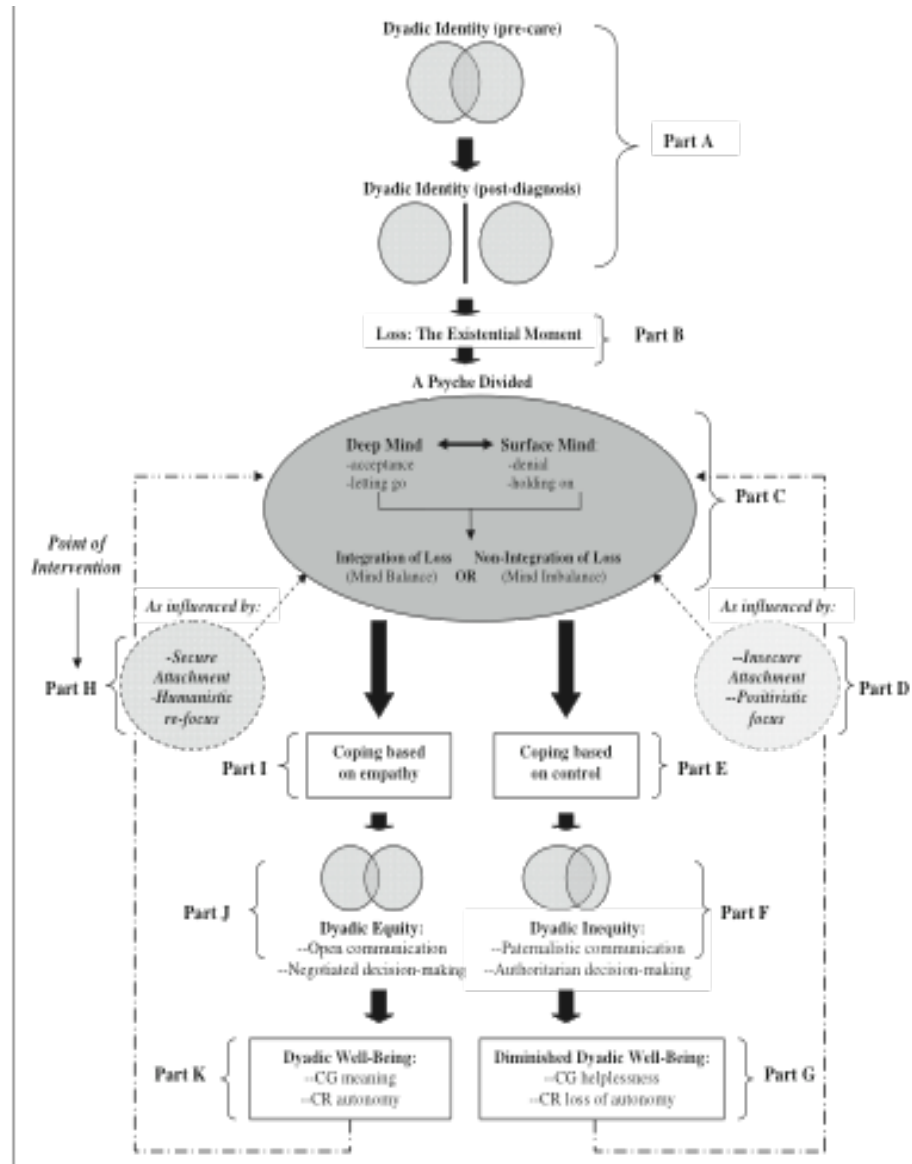


Figure 2.1 Existential Loss (Piiparinen & Whitlach, 2011)

Synthesis and integration. Throughout the literature, the theme of finding meaning and meaning making through empathy as a life and health enhancer is pronounced. I have staked a commitment to a particular perspective—Scheper-Hughes & Locke's (1987) framework for approaching health care issues by considering where the focus lies on a spectrum from phenomenological self through social and political bodies. The political body represents cross-sectional and epidemiologic studies, attempting a broad generality with the identification and management of bias. This represents a bio-medical view of health and a *disease* perspective, describing a pathophysiological process as opposed to illness as the subjective and daily meaning of that experience. Our social body is lived through our mutually interpreted family and community relationships against the background of competing political ideas and philosophies. Most research presented is of the social body without a clear understanding of the phenomenal body. The phenomenal body is the focus of my proposed research.

My study meshes the phenomenal body with the social and political in that how we know anything begins with *the way* we know and experience ourselves through a fusion of sensing and being sensed, as well as our psychic or mental actions. Just as our hand feels and is felt, we are the inquiring subject as well as the object of that inquiry (Merleau-Ponty, 1945/2008). To get beyond this internal loop, knowing requires the acknowledgement of others and their experiences, or empathy. *My I*, my set of personal characteristics and pattern of my flow of consciousness, requires the acceptance of other egos and their flows of consciousness to get beyond the solipsistic cycle and cast consciousness toward others and the world. According to Edith Stein (1989), empathy is a requirement for consciousness of

anything. Sawicki (1998, p. 13) has diagrammed this *I* consciousness in a field of *Is*, as shown in Figure 2.2.

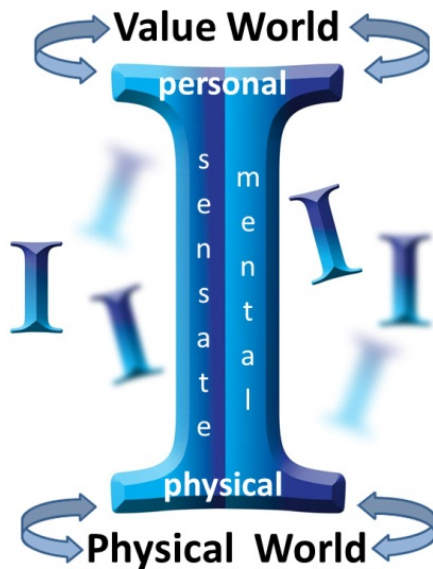


Figure 2.2 Sawicki's Field of *Is*

This is inter-subjectivity is a more appropriate expression of what goes on in the oval of Piiparinen and Whitlach's diagram. It is not one's own mind, surface and deep, but the fluctuation between aspects of personal and physical in a field of *Is* that promotes the chronic ambiguity, which results from the condition of being an independent *I* and dependent at the same time (Stein, 2002). Given that, the interdependence of the phenomenon of dementia within the context of husbands caring for their wives needs description.

A great deal of the research literature on family caregiving is concerned with perceived burden and its detrimental consequences to health; this literature has been the result of surveys, standardized psychometric instruments and scales that necessarily remove context variables to look for and analyze risk factors and facilitate causal analysis. Terms like *coherence* or *meaning making* in the face of suffering bring up the spiritual nature of

human being, which is a difficult topic for science, but was not for Stein. Every *I* has a personal series of unfolding experiences with unique appearances, not as extending rays, but as intricate connections of relationships that become an experiential context, moving along the stream of consciousness through personal motivations, which Stein attributes to the spirit. The spirit is subject to rational laws and its experiences are intelligibly related, and it is localized in the body.

According to Sawicki's diagram, as it represents Stein's theory of person and consciousness, *I* have private, privileged interface, both personally with the value world and organically with the physical world as an individual *I*. My empathic interactions with other *Is* occur through sensate and mental acts (the shaft of the diagram) because they follow rationally, in that the flow of motivations can be followed. My interpretation of data is based on Stein's theory of person and consciousness.

Chapter 3

Methodology

Phenomenological Study as a Qualitative Research Method

The purpose of this phenomenological study is to describe the experience of dementia as lived by couples at the point where they are considering the use of adult day services. The research questions for the study are:

1. What is the meaning of dementia to husbands caring for their wives with dementia?
2. What is the meaning of dementia to wives receiving care from their husbands?
3. What is the meaning of dementia spousal care giving/care receiving with respect to nursing care?

Husbands represent a minority of caregivers for those with dementia (Alzheimer's Association, 2012), however, they report the least amount of burden, a higher sense of coherence, and less depression when compared to wives, daughters, and sons (Conde-Sala, Garre-Olmo, Turro-Garriga, Vilalta-Franch, & Lopez-Pousa, 2010; Valimaki, Vehvilainen-Julkunen, Pietila, & Pirttila, 2009). By selecting male caregivers who report more benefit than burden in the care of their wives with dementia and conducting interviews with this dyad, I hoped to gain insight to the ways they perceive, categorize, and find meaning in their everyday experience of dementia.

In qualitative research, the researcher/observer is situated in a natural setting, rather than in controlled experimental conditions, to transform the world as experienced into representations that can then be analyzed. Representations, including field notes, conversations, interviews, photographs and memos are the data used to describe the situated meanings and interpretations of the individuals or groups studied (Denzin & Lincoln, 2005).

Phenomenology is a specific type of qualitative research that focuses on the lived experience or subjective reality of a particular phenomenon, in this case dementia. When Bryden (2005) talks about the value of human touch as she experiences progressive dementia, it is not the amount of pressure per square inch or duration of contact that she is talking about, it is the sense of, “touching our emotion and spirit,” (p.138), and entering the reality of those with dementia. In phenomenological language, valuing is an example of constitution, the mental act of consciousness that renders meaning and becomes, from a field of possibilities the intention of that act of consciousness. Smith (2007) describes intentionality as “...an act of consciousness, performed by a subject, is directed via its content toward an appropriate object... where this content rests on the subject’s background understanding of a horizon of meaning about such objects” (p. 209).

This constituting of meaning within the context of couplehood impacted by the wives’ developing dementia is what I am looking for in this project and why a deeply subjective outlook is assumed. The world is perceived and reflected inter-subjectively with our own perceptions validated or rejected as we compare ourselves to others within and outside our cultural, social, and political lifeworld. Give and take is part of human relationship.

Husserl (1913/1983) describes the movement of the phenomenological ego stepping back from the phenomenological object to a self-reflective reference that brackets the object of interest in order to analyze the way our consciousness conceives it. This is the process of phenomenology that penetrates the natural, un-reflected view that Arp (2004) describes as a “cognitive interruption.” This is the initiation of philosophizing preceding a movement from the routine, mundane mode of existence, through scientific reflection to transcendent self-

reflection, phenomenological self-reflection and ultimately inter-subjective phenomenological self- reflection. *Bracketing* is the central feature of phenomenology that moves the focus from the object to consciousness of the object, beginning the process of “eidetic variation” or consideration of all the possible permutations of meaning that an object may hold in order to determine what it is.

Giorgi (1985, 2006, 2009) adapted Husserl’s philosophy of to a descriptive phenomenological method in psychology. I used a modified version of this method in my study. His method includes several steps. Interviews are conducted to collect stories and narratives from participants that represent the un-reflected, naïve, natural attitude. These interviews are transcribed verbatim with annotations for pauses or emotional displays and this becomes the data. These steps are followed in analyzing the data: 1) The scientific phenomenological attitude is assumed for analysis of the verbal data by first reading for a sense of the whole; 2) Determining the smallest “meaning units”; and 3) Transforming these units from their meaning in the natural attitude to their phenomenological meaning. The researcher completes these three steps and then articulates the invariable *psychological* meaning structure of the experience. These steps and diversion from them will be discussed in more detail in the analysis section, but first it is important to note Giorgi’s definition of psychology, given Husserl’s criticism of psychologisms in the *Prolegomena to Pure Logic*, (Husserl, 1900/ 2001). According to Giorgi (2009), *psychology* pertains to “...how human subjects present in the world to themselves and how they act on the basis of that presentation”; this is generic and a-theoretical.

"Meaning" From a Nursing and a Phenomenological Perspective

The American Nurses Association (2003) defines *nursing* as, “The practical promotion and optimization of health and abilities, prevention of illness and injury, alleviation of suffering through the diagnosis and treatment of human response....” (p.6).

The American Nurses Association definition is very broad and leaves open the definitions of *health* and *human response*, which are critical to addressing the third research question, what do the results of the phenomenological analysis mean in the context how “meaning” is defined in nursing.

The commonality between definitions is “how they act”—the subjective human response to objective circumstances as we constitute meaning. Understanding human response, suffering, and caring are central to the art and science of nursing. For the purposes of this research, Giorgi’s psychological meaning and nursing meaning are congruent. I define *nursing meaning* as understanding how different acts of consciousness encounter and constitute dementia within the lifeworld of care giving/ cared-for dyads.

The “intentional sense” of phenomena is a significant aspect of meaning making in human response and a fundamental aspect of nursing science focusing on empathic understanding of another’s experience. Nursing is generally regarded as practice discipline involving a helping process, both an art and a science. As noted in chapter 1, there is a wide range of philosophical positions within the field of nursing on what nursing is and how it is done. These views vary according to how the basic concepts of nursing interaction with persons/clients within society/environment with respect to health (Chinn & Kramer, 2004), as well as praxis, “...the synchronous conjoining of ‘thinking’ and ‘doing’,” (Lutz, Jones, & Kendall, 1997, p. 24), are understood.

Merleau-Ponty (1945/2008) describes the phenomenological view of human being and experience as never static or separate from the lifeworld; we are engaged in it because it is a condition of our consciousness. Our embodiment is also a condition of our consciousness. Perception involves the synthesis of phenomenological data within the structure of logical relationships. Our interpretations change as we perceive shifting appearances of the same phenomenon. Complete knowledge is not possible from the subjective viewpoint, yet that is our only access to knowledge. This does not suggest that rocks do not exist before our perceptual awareness of them, but our human knowledge of a rock as a hard mineral aggregate depends first on our perceptual awareness of it as a tool or weapon, for example, as we distinguish it from background. Perceptual inconsistencies, for example optical illusions, are not imperfections, but the nature of consciousness. This is why a rigid method contradicts phenomenological inquiry. Misiak and Sexton (1973) identified several criteria necessary to consider a method phenomenological: it must be based on Husserl's principles, it studies experience as immediately given (non-reflected naïve description), it frees the researcher from preconceptions, and it results in description. Giorgi's (2006, 2009) method meets these criteria.

I recorded narrative descriptions of dementia as experienced and described by both spousal caregivers and care receivers. These data represent experience within the *natural attitude*—views before analysis or reflection. The analysis required a shift to the phenomenological attitude, which meant changing the focus from dementia itself to the way mental acts of the research participants aim at a phenomenon and give it meaning.

Phenomenologically, what we know is inseparable from being, making subjectivity a tool of research. My area of practice has been geriatrics in the long-term care setting where

communication or cognitive deficits often shift the focus of care to the physical body. This research elicited and describes what the day-to-day experience of dementia in spousal dyads of the carer/cared for is, which is why phenomenology is an appropriate method. I wanted to know what the essential meaning is to the participants, what remains unchanged despite the variance in the particular individual experience.

As a phenomenological researcher discussing method, I propose several caveats. Using my subjectivity as a research tool required me to maintain an attitude of wonder and sensitivity to my own already-created meanings and preconceptions, as well as sensitivity to formulaic procedures or methods of investigation that could format, rather than reveal, results. According to van Manen (2007), a research method is an investigative technique that should maintain deep resonance with the interests and motivations guiding us to our chosen fields of work and study. Subjectivity is a tool of research. Believing that attaining a pre-supposition-less attitude is possible or necessary is contradictory. I will continue to comment on use and management of subjectivity in this research.

Research Design

Participants, sampling, sample size, and recruitment. I used *purposive sampling* (Munhall, 2007) to identify those who have experienced the phenomenon of concern, were willing to participate and who spoke English. By purposive sampling, I looked for husbands whose need and desire to tell their story held the potential for information-rich data, full of details of day-to-day living with a wife with dementia. In phenomenological research, there is no set sample size, though Giorgi (2009) recommends a minimum of three participants. Graneheim and Jansson (2006) had three participants in their phenomenological investigation of living with dementia and disturbing behavior, while Edvardson and Nordvall

(2007) studied six participants' experiences of being in a psycho-geriatric unit with dementia. Morse (2000) points out that many factors including type of qualitative research and intensity of expected data figure in the determination of sample size, but there are no rigid guidelines. *Intensity of data*, for the purposes of this study, refers to very specific and highly textured detailed description of lived events (Todres & Galvin, 2005). At the point of interview, the couple would be thinking about adult care services; the phenomenon of dementia firmly within their lives, offering the possibility for many examples and stories of what it is like. Given the predicted length and intensity of the interviews, I had planned to recruit a sample size of five couples, based on potential to generate concrete descriptions of lived experiences (Cohen, Kahn & Steeves, 2000; Munhall, 2007). This requires intact communication ability among the women with dementia. I wanted to maintain an approach without formulaic measurement; though I am aware that there are tools to measure verbal fluency, I did not want to establish any set measure of verbal fluency as inclusion criteria.

The participants were to be five couples consisting of a wife or long term companion with dementia and husband/ long term companion caregiver who met the following inclusion criteria: Wives: 1) Age 70 and older with a reported medical diagnosis of senile dementia of the Alzheimer's type (SDAT); 2), community-dwelling; 3) ambulatory; 4) English-speaking; and 5) began attending day care services within the last 2 months, or are currently contemplating service use, aware to some degree of their diagnosis. For the caregivers the criteria were: 1) Married to and/or living with the person with dementia [PWD], providing the majority of care; 2) English-speaking. For both groups, the ability to take part and interest in participating in a video-recorded interview were required. The legal status of relationship was not important to the information I was seeking. I wanted to know how

dementia is lived, how it enters consciousness from the viewpoint of women experiencing this phenomenon as well as that of the men who have known them and shared their lives. Chapter 4 includes my description of modifications to the initial research proposal that came about as a result of recruitment difficulties.

The primary strategy for recruiting participants was networking with professional contacts and providing information flyers (see Appendix D) at clinics, adult day centers, dementia support groups, and assisted living facilities. Recruitment continued until the sample size was reached. Informed consent was obtained from both members of the dyad after the study aims, procedure, and selection process was explained in clear, simple vocabulary. Principles of process consent (McKeown, Clarke, Ingleton, & Repper, 2010), including ongoing assessment of continued consent, were followed. This approach was taken to maintain a transparency of consent that values the participant over the research process. The dyad was assured that participation was entirely voluntary, and that there would be no payment for participation and no change in care should they decline. Once qualification for inclusion was established, risks/benefits were reviewed, and participants agreed and signed the informed consent. I then made an appointment for a home visit with the couple to conduct and record the interviews. I conducted interviews with both spouses present, anticipating participation of both. I also expected contribution of the husband when I was directing questions to the wife. I did not set any parameters for who was to answer when. I also demonstrated how the recording worked at the beginning of the interview to make sure the couple was comfortable with it.

Protecting participants' confidentiality. Data collection included audio-recorded interviews and transcriptions of conversations from the recordings. Basic demographic information was collected, including age and years married or together.

The potential risks of the data collection methods used include psychological harm and breach of confidentiality. To mitigate any potential breach of confidentiality regarding conversations or events occurring during any of the visits, materials were coded so that no personal identifiers were used on any collected data. All demographic information and data files are identified only with a code number (i.e., *Interview 1*). All study materials linking participants' names/addresses/etc., were stored separately from transcripts in a locked filing cabinet in the committee chair's locked office. After completion of the study and the dissertation has been defended, shredding will destroy all names/addresses and links to code numbers and audio recordings will be deleted. Because linguistic data obtained during the interviews could cause emotional upset, the plan was to manage this with patience, reassurance, and, if needed, discontinuation of the interview and rescheduling, or immediate discontinuation of the interview, none of which occurred. All participants paused when they felt like it, but none elected to cancel their participation.

Dementia is a growing issue with the aging of the population. Participants seemed to feel a sense of satisfaction participating in a study that might help others in the future. They seemed to appreciate having the opportunity to describe their personal stories of how dementia entered and exists in their lives. All participants were informed that this research would add to the body of knowledge on the meaning of dementia caregiving for people with dementia, and the experience of dementia. Participants also were told that it would aid those

supporting informal caregivers and expand empathic understanding of dementia among health care professionals.

Qualitative interviewing. I audio-recorded interviews with six husbands and two wives, transcribed the interviews, and analyzed the verbal data using Giorgi's method. The completed study included only audio data, so no visual data underscored or clarified verbal responses as was originally planned.

Phenomenological interviewing is a specific type of qualitative interview taking place within an interpersonal context, focusing on understanding another's first person world, which allows for imprecision and personal meanings. The participant determines the flow of dialog (Thomas & Pollio, 2002).

Though I used my own subjectivity as a tool and focused on the lived experience for this study, phenomenological reduction is a process that begins in subjectivity, steps back from it, and breaks away from the lifeworld-embedded experience. The purpose of the research was to delve beneath the cultural context of "knowledge" by examining the ways in which that knowledge came to be, the *givenness* of the phenomenon, through acts of consciousness (Giorgi, 1986, 2009). The descriptions were all self-selected by the participants. The verbal data conveyed specific instances and examples that were detailed and focused on immediate moments when the phenomenon presented itself to the couples' consciousness within the pre-reflective natural attitude (Giorgi, 2009).

Munhall (2007) describes a process of *decentering* and *unknowing* in interpretive phenomenological research interviewing in which the interviewer is acutely aware of language and its potential to influence response (i.e., "Do you think it was because..."), and therefore recommends broad open ended questions. Although the researcher does not control

the interview there is a certain amount of direction helping the participant focus on specifics or comparing instances of their experience of the phenomena which is balanced with following divergence from the phenomenon and repetitious descriptions (Thomas & Polio, 2002). At times the participants seemed to deviate from the discussion of dementia, but rarely did I lead the interview back to topic, because I was not sure of what the participant was trying to communicate; I felt I had to be cautious of the possibility of missing some broader context of meaning within the discourse. Several examples of this are described in the following chapters.

Interview questions. The practice of de-centering and maintaining an unknowing stance are important to avoid formatting responses according to my own preconceived notions. This requires flexibility in questioning. Some of the questions I used are as follows:

- What stories can you tell me?
- Would you give me examples of how your wife is experiencing dementia?
- What kind of care do you provide?
- What is it like being cared for by your husband?
- What kind of help do you need?
- What is important to know about you?

These questions initiated the interviews. Standard probes were used to encourage further description, such as: Please tell me more about that. Would you give me an example? Do you remember how you felt when that happened, would you elaborate? Patience and silence were useful prompts when the participants paused.

The purpose of videotaping was not to emulate visual ethnography or visual sociology, but to view the lifeworld from the familiar in order to adopt a phenomenological

gaze. Given that intent, videotaping was a representation in its own right, not only capturing expressions and gestures, but attributes such as hairstyles, clothing, grooming (Harper, 2005).

On one visit to a patient in a dementia unit, she was well dressed and groomed, except for exaggerated eyebrow pencil and mismatched earrings. Either of these images could be what T. S. Eliot (1922/2011) popularized as the objective correlative. Eliot felt this was the only way to express emotion in art, by finding an object or situation as representation. I felt this would be an additive element to audio-recording. Adding sensual and contextual data to transcriptions of the interview is particularly important when considering cognitive and verbal impairments of dementia. I understood that credibility, the true representation of behavior, could be impacted by participant reactivity, observer bias, and maintenance of consistent data quality (Spiers, Costantino, & Faucett, 2000). When I offered the participants a choice of only audio-recording, they all refused the video recording. As reported, these changes to the protocol are discussed in Chapter 4.

Analyses

Giorgi's method was adapted and used to analyze Linguistic data. The analysis included:

- 1) *Reading for a sense of the whole.* Giorgi (2009) points out that this is common to most qualitative analysis and in fact seems prudent for any kind of analysis. Parts and wholes have a particular relevance to Husserl (2001/ 1900). Because the research goal is to identify the structure of the act of consciousness, in this case the experiences related to caring in dementia, the whole is the abstract about which the individual experience gives glimpses between innumerable gaps. The process involves discerning the essential aspects of the parts to understand the whole as

distinguished from the particular individual expression. The audio-recordings were listened to repeatedly in order to gain a sense of the whole. Audio recordings were transcribed verbatim into SuperHyperQual (Padilla, 2004), a Macintosh edition software for the management of text analysis, onto text data cards as shown in Figure 3.1. Behavioral descriptors were entered in the notes section.

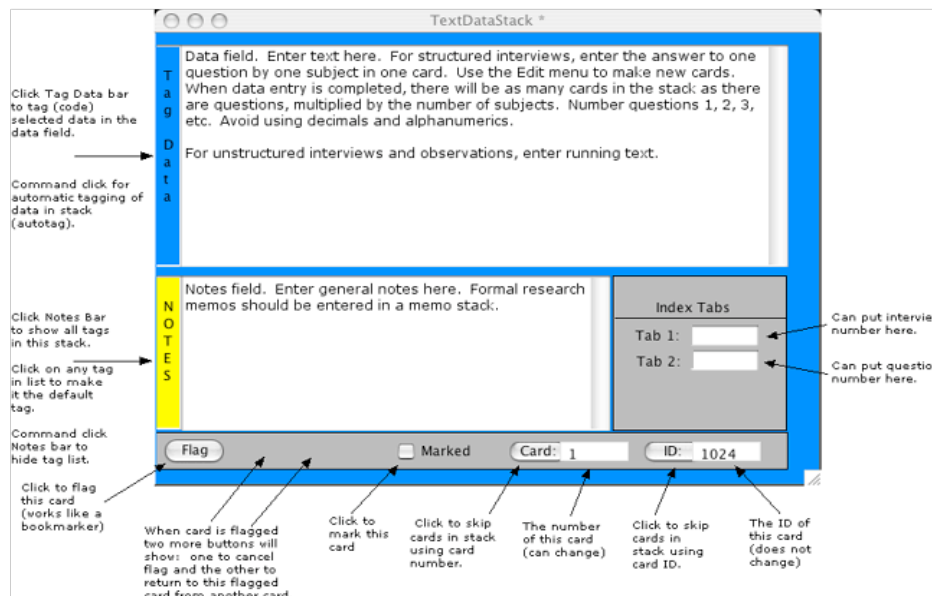


Figure 3.1 SuperHyperQual Data Text Card (Padilla, 2004, p.7).

- 2) *Determining the smallest “meaning units.”* Meaning units are points in the narrative where meaning shifts (Giorgi, 2009), and they consist of phrases, sentences or paragraphs that are intersubjectively recognizable as elements of experienced meaning. This step is a process of making the data more amenable to analysis by identifying the intentionality or the *aboutness* of the data. This is done by returning to the beginning of the text and working through to the end and separating the text into meaning units. Audio-recording was continually reviewed. Meaning units

“tagged” as text data were coded and analyzed for meaning. Notes on those procedural decisions were maintained separately to follow the eidetic variation. As each meaning unit was “tagged” this became an exemplar with a corresponding card (see Figure 3.2).

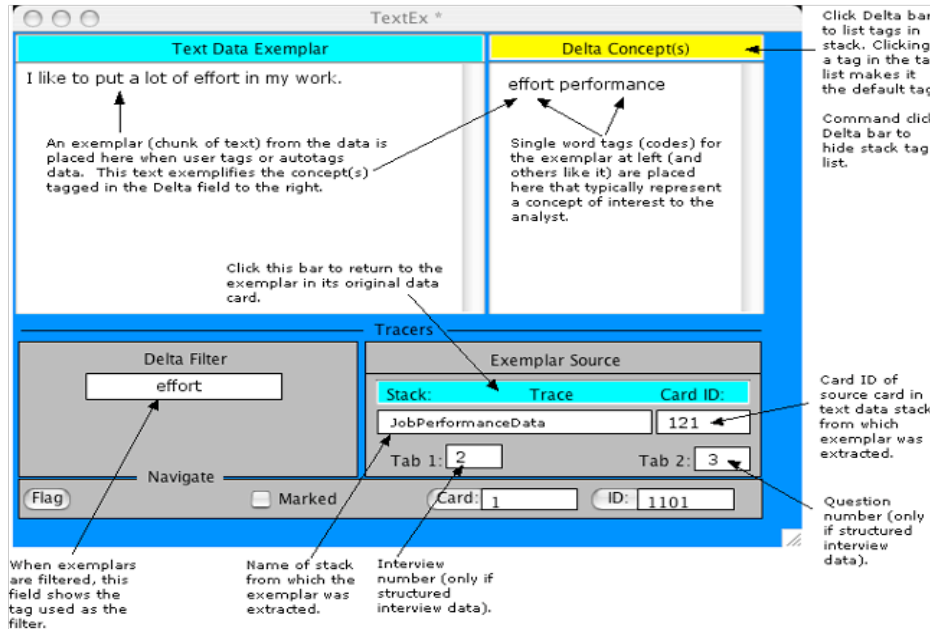


Figure 3.2 An Exemplar Card for Text Data (Padilla, 2004, p. 11)

3) *Transforming these units from their meaning in the natural attitude to their phenomenological meaning for nursing.* This is the critical feature of the analysis.

With this step we transform the lifeworld experience to the phenomenological essence. The researcher returns to the now familiar narrative and begins

“interrogating” meaning units. Giorgi (2009) recalls that for Husserl, meaning is based upon separate acts of consciousness: “Signifying acts -> precise fulfilling act -> act of identification” (p.133). This becomes the root of this step. Acts of

consciousness include specific acts of perception, imagination, judgment, each directed at a specific object. Husserl writes (1900/2001) "...we grasp the ideal unity of a meaning in the light of the act-character of signification; this signification's peculiar tincture distinguishes the meaning of a given expression from that of one which differs in meaning." (p. 133). Within any single act of consciousness there is a correlation between the ideal, the immediate experience, the sense in which the object is intended including content and how content is processed, the about-ness of the content, and the noetic aspect or the eidetic sense—the universal aspect that is sought through the eidetic variation of the phenomenological reduction, a process of iterative consideration of essential from nonessential. Particular acts of consciousness aimed at an object will have a situated content particular to a particular time and context, which is its noetic aspect. By identifying what this particular act has in common with all other similar acts, we can derive its noematic, universal, timeless aspect. Giorgi maintains that this act/ object correlation is the key to rigorous analysis, as long as the initial transcribed description was sufficiently concrete and rich in details. The act of the describer and the object of his/her description can, in a sense, be held apart and studied from the perspective of the analyst. "The noetic-noematic relation is a way of entering the consciousness of the other and accurately exhibiting precisely the parts of the experience that contain the lived meanings that are the focus of the descriptive task" (p. 105).

Another aspect of analysis is that in lived experience—the natural attitude—ambiguity is always given and always present (Merleau-Ponty, 1945/2008). All experiences we have of myths, illusions and dreams are possible because of the interplay of appearance

and reality. In our experience appearance is reality because we are not entirely aware of ourselves and yet not totally ignorant. Dementia as intentional object within the acts of caring/being cared for becomes a conceptual interpretation apart from the dementia itself. Husserl uses the example of Napoleon to explain this “intentional” aspect of object. We are interested in a particular sense of Napoleon, for example, “the victor at Jena” or “the vanquished at Waterloo.” This is the intentional sense, the subjective meaning of the particular experience. Analysis involves reading the meaning units with an already heightened sense of the whole to understand the way in which participants are connected to the life-world of dementia through the patterns and connections of their assigned meanings.

Husserl (1913/1983) writes about “givenness” and evidence in parts three and four of *Ideas Pertaining to a Pure Phenomenology and to Phenomenological Philosophy, Book One*. Givenness has broad and narrow meanings. The broad meaning is the way in which the ego fixes upon or seizes upon datum, for example by looking, touching, fantasizing—how we become aware through the appearance of the phenomenon. Appearance is always imperfect because perspective is limited and continuously blended into eidetic possibilities (how does this particular example represent the entire category). Throughout the literature review these aspects of the experience of dementia whether personally or while caring for a spouse this was seen. Receiving a diagnosis, finding yourself in an area of town with no recollection about getting there, realizing that your bank account is swelling because your wife has forgotten to pay the rent bill are all examples of givenness, as well as the rich, concrete description that Giorgi talks about. Experiences like these change the eidetic possibilities. As the category is gradually understood to be dementia— recognizing that there is something wrong with our pattern of understanding the lifeworld—our natural attitude becomes

disrupted. The role patterns and structures that have established identity are questioned. The ego’s about-ness becomes itself and the most proximal relationship—the spouse. Giorgi (2009) presents a matrix approach (pp.146–153) in which the meaning units are numbered on the left side with meaning transformations on the left.

Rephrased meaning unit from first to third person	1 Phenomenological reduction, eidetic variation. Varied, concrete descriptions become more generalized by looking for themes.	2 Phenomenological reduction, eidetic variation. I will do this in several steps to track the variations.	3 Phenomenological reduction, eidetic variation—until essential quality is identified, no further reduction needed. This is a description of the experienced phenomenon.
Next meaning unit, etc.			

Figure 3.3 Giorgi’s Analysis Matrix of Meaning Units

I organized data according to Giorgi’s matrix to discover and describe the essential structure of the experience for each of the six couples. This transformation of meaning units is described in more detail in Chapter Four, because explaining phenomenological method is difficult without showing its’ responsiveness to the data, and eventual findings.

Each story I collected was an opportunity to transcend the naïve life world by identifying the totemic, collective experience. This can be read as eidetic variation to the essence. Watson (2012) points out that Giorgi’s methodology is orthodox in its process and suggests that more innovative means of presentation may be required to represent the full, dynamic experience of emergent meaning, insight, and use of language.

Rigor

The goal of descriptive human science is the discovery and basic portrayal of the structure of modes of consciousness rising from human interaction (Polkinghorne, 1983). In quantitative research strategies, maintaining validity and reliability underlie the strength of knowledge or truth claims; in qualitative research it is rigor and trustworthiness (Lincoln & Guba, 1985; Guba & Lincoln, 2005) representing the similar idea of integrity in the plan and process of research. A significant aspect of the different approaches to science is that if we believe that there is verifiable, constant and objective knowledge then internal and external validity and reliability are important values in the judgment of method and outcome.

Phenomenological research holds that there is an inter-subjective, social creation of reality with respect to the experience and meaning making of human beings, which is the aim of inquiry. Authentic, trustworthy research results within this kind of holistic view of a human “... as a unique, valued and precious person in and of him- or herself ... honoring the unity of mind-body-spirit, continuous with the larger environmental field” (Watson, 2012, p. 19) necessarily denies any correspondence view of truth.

Giorgi (2006) discussed misguided approaches to verification of findings including participant and expert reviews. In the first case, participants are asked to review the outcome description and in the second experts in the field review the results to see if it is consistent with their experience. Either of these approaches puts the participants rather than their experience as the focus of the research. It also diminishes the importance of the phenomenological reduction, which removes or brackets the fact of the phenomenon; the phenomenon must stand out from the individual experience. Giorgi does not explicitly

address rigor (2009) but does maintain that given the same narrative any phenomenological analyst diligently following his method would reach the same resulting essential structure.

Munhall (2007) suggests criteria to evaluate merit that pertain to a reader's affective response (i.e., resonance and raised consciousness). De Witt and Ploeg (2006) suggest five expressions of rigor in interpretive phenomenological research: balanced integration of the philosophical framework, openness demonstrated by a systematic accounting of decisions, concreteness of exemplars, resonance (the felt effect of reading results) and actualization of findings in the future.

I have demonstrated rigor by providing an audit trail of all meaning unit designations and transformations to demonstrate consistency with the theoretic framework as well as general conformity to phenomenological method so that any other phenomenological researcher can use the data to verify the analysis (Giorgi, 2006, 2009). I clearly integrated my philosophical framework into the analyses, provided clear description of the analysis and resulting variations from the original verbal data using Giorgi's (2009) matrix. I provided a description that resonates with experience and existing literature. I have maintained awareness of current controversies in qualitative research (Guba & Lincoln, 2005) that see imposed regulatory norms for achieving validity paradoxical given the dynamic uniqueness of human interchange and integrated this into my reflections on method in Chapter Five..

Limitations of the Study

Limitations of the research are clearly related to the validity of the assumptions of descriptive phenomenological research, which are:

1. The structure of another's pre-reflective consciousness can be studied by elicitation of narrative descriptions from experiencing participants.

2. Everything we know originates from the privileged first person experience.
3. Results of phenomenological research can be generalized.
4. Our access to objectivity is through inter-subjective constitution.
5. Human consciousness shares common structure, though how it is layered is personal.

Because language provides the data, linguistic facility of the participants and researcher is a limitation and presents a layer of reflection with respect to the lifeworld. Once we consider our choice of words or describe a sequence of events in a narrative, it is no longer the naïve un-examined view. Verbal fluency often is affected in people with dementia, requiring augmentation with body language and assistance with word finding is also found in those relating emotionally charged memories. Researcher bias is another potential limitation common to qualitative inquiry, because one's own subjectivity is a research tool. The danger is finding what you are looking for instead of discovering what is there. An audit trail was maintained to account for decisions and rationale for interpretive decisions.

These assumptions and limitations that I had projected at the beginning of the study were constant companions during the interviews, designations of meaning units and ultimate findings of the study. I return to them for more consideration and discussion in Chapter Five.

Summary

The detailed rationale for a phenomenological methodology of inquiry to the experience of dementia as lived by caregiver/cared-for couples stems from the understanding that empathic understanding of human phenomenon is an essential basis for nursing care. Phenomenological research is particularly suited to this aspect of nursing research because it

explores phenomena as lived by our patients and produces a description of what is noticed and felt in the construction of meaning.

The specifics of method were described including sampling, data collection, analysis and ethical protection of participants. Limitations of the study were identified along with strategies for maintaining trustworthiness.

Chapter 4

Findings

This chapter presents the reasons for changes made to the protocol, a brief characterization of the study volunteers, the process of analysis, and findings that answer the first two research questions.

Changes to the Protocol

I began recruiting for couples who met my inclusion criteria in October 2012, following approval from HRPO. I sent out flyers to colleagues caring for geriatric patients, home care agencies, and adult daycare facilities. I also attended Alzheimer's support groups where I gave a brief introduction to the study and passed out flyers. During this time I spoke to many prospective volunteers who declined to participate for a variety of reasons. Examples for refusal included not wanting to be video-recorded, not wanting me to go to their homes (one gentleman was "ashamed" of his poor housekeeping), fear that their wives would be upset, not having the time, not considering day care services at all, and/or the belief that their wife's dementia was not of the Alzheimer's type. After 2 months, I had not enrolled any volunteers.

After much deliberation and reviewing the purpose of the study, I determined that the inclusion criteria were too narrow, and contributed to difficulties with recruitment of participants. I found that I was asking too much in the way of time and intimacy by asking to video-record in people's homes. I had narrowed the inclusion criteria to the point that it excluded many people who were otherwise eager to share stories of what their lives are like. I also realized that many of the caregivers are protective of their wives and would prefer not to expose them to any possible embarrassment by asking them to talk about their own

dementia. As a result of my experience, and with the agreement of the study Chair, I filed a modification of the original protocol. The modifications all related to expanding inclusion criteria. I no longer specified senile dementia of the Alzheimer's type, or video-recording; audio-recording would be permissible if participants made that choice. I included couples in whom the wife was in assisted or long term care. I accepted husband volunteers alone, as well as husbands whose wives had died within the last year. The husband could decide the location of the interview—a private room in a care facility, library or other public place if they did not want to do it at their home. The goal was to collect descriptions of what the day-to-day life is like for the couples. Six men volunteered for the study as well as two wives. The interviews each lasted 48 to 78 minutes. One of the wives had appropriate decisional capacity as determined by the screening tool (see Appendix C) and was able to participate in the interview. The other wife was nonverbal during most of the interview, speaking only several words. Two of the volunteers were caring for wives from second marriages. One couple had no children, two couples had one child, one had four, and one had five children.

Volunteer Interviews

Interview 1 took place in the volunteer's apartment. He was recruited through the nurse associated with his independent living facility. His wife had died 8 months earlier, after 30 years of marriage. When we met, I reviewed the inclusion criteria and he acknowledged meeting them. During the interview, though, he minimized the dementia aspect of his experience and focused most on his problems with healthcare, first in a rural area and then after they moved to be closer to medical care. His wife had a coexisting bipolar illness that he believes was misunderstood by the healthcare team and poorly managed. They had no children, and family members live in another state and visit rarely.

He details the physical struggle of care, which includes lifting and transferring a wheelchair-bound heavyset woman for personal care and hygiene, as well as the emotional turmoil of trying to communicate with his wife of 30 years who had expectations he could not understand and could not fulfill. He also sees his wife's behavior stemming from her anger, frustration, and feeling of helplessness. Eight months after his wife's death he was still second-guessing his actions and decisions, wondering if he missed anything, because the experience has been something of a mystery to him. At one time they were told she had frontal-temporal dementia, but he never saw any signs, which to him meant, "she never wandered." He did not seek out any information regarding dementia. The biggest problem for him was her aggressive and, at times, combative behavior, which he understood as related to bipolar disorder.

Interview 2 was with a couple recruited through a brief introductory talk at an Alzheimer's Association support group. The interview took place in a meeting room at the Alzheimer's Association. This was the shortest of the interviews. I conducted a decisional capacity screen (see Appendix C) she passed, as she was able to repeat the purpose and procedure of the study to me. They have two children who they were taking along with grandchildren and their children's spouses this summer on a cruise to Alaska to celebrate their 50th wedding anniversary. He described a very gradual change in their relationship. After his wife repeated an observation to the same group of people, forgetting she had just said that same thing he started noticing more cognitive changes, and they brought it to the attention of their primary care provider, who responded by doing some testing and prescribing a medication. Further indicators of cognitive decline led to a neuropsychological evaluation and presumptive diagnosis of Alzheimer's, which they pointed out jokingly, can

only be definitively diagnosed on autopsy, for which they are not ready. His wife stopped driving five months ago. He has had to take over many of the responsibilities she held previously. She was reading less and often forgot what she'd read; she would watch a game on TV and immediately forget who won the game. They understood the situation as a progressive disease without hope for improvement. She was the organizer through earlier years, and now this was his job. He managed the finances, the shopping, transportation, medical visits and medication management. She got nervous when asked for any specific information because she did not "want to say something stupid." Their children were aware of the situation and were helpful. They had friends in similar situations with whom they socialized. They belonged to a church that was developing a Saturday afternoon social hour for members with dementia and their families. She joked that if she needed help going to the bathroom her husband would run away, to which he replied, "We do what we have to do." He missed the companionship they once had. She had a college degree and held positions that required multitasking. Since the time she was a girl, growing up on a farm, she worked hard at everything. She told me that now felt less essential.

Interview 3 was with a husband recruited through the nurse at his independent living facility. The interview took place in the facility's hobby room. He and his wife had been married 64 years. Together they developed multiple business enterprises, as well as managing their ranch where his wife "rode just like any other cowboy." They had two living daughters and a son who died in an accident in his teens. The husband described a very tight-knit family, including 11 great grandchildren who lived in the area. He told me that he does not like to admit his wife has dementia because that implies something is wrong with her. He feels the frustration of trying to please her and realizes she resents him taking over

responsibilities that had been her domain. His wife's difficulties accelerated after a recent CVA and hip fracture. Additional challenges include the realities that she is hard of hearing and he is blind. They live in an independent living facility that is directly connected to a nursing home.

Interview 4 was with a husband alone, referred to the study by another volunteer. He and his wife had been married 47 years and had two children. The interview was conducted at an Alzheimer's Association meeting room. He told me his wife was relieved when she got a diagnosis of vascular dementia rather than Alzheimer's, which she perceives as more ominous and threatening. She is ambulatory and continent. He tells me that he signed on "for better or for worse," and that he is doing the best he can. He feels like he is living alone because their communication has dwindled so much and consists mostly of her asking permission for almost everything she wants to do, and him acting as director of her day-to-day activities. She feels she is a burden and has asked him if he wants to divorce her and has told him to put her in a nursing home and forget about her. He did not describe his experience as a burden, but instead as a wearing and tedious, repetitive grind.

Interview 5 was with both the husband and wife. He was referred to the study by a personal trainer at the community center they frequent almost daily. He was a widower with two children when they married 37 years ago. They have a son who lives in town, with whom they have dinner about once a week. She was unable to answer any of my questions determining decisional capacity and only spoke when her husband tried unsuccessfully to get her to repeat his counting to ten. She makes brief eye contact but does not return a social smile. The interview took place in a room at the community center. He tells me he is angry about their situation and particularly with the field of psychiatry because they have been

unable to help his wife and, in fact, have not really been clear on a diagnosis, although the psychiatrist and neurologist have told him she has frontal- temporal dementia. He understood this to mean a dementia that involves cognitive impairment, but he believes the diagnosis is inaccurate. He has experienced health care providers as pleasant and kind but negative, in that they offer no hope of improvement or cure. He is the only care provider for his wife, takes her everywhere he goes, which includes a mile of walking every day at an indoor track at the community center. This daily exercise is to keep her in good physical shape for when a cure is found. His wife is incontinent of urine. This and the related bathing and hygiene tasks as well as resultant laundry are the most difficult aspect of care giving for him. “She wears disposable briefs, and I got her on top of that, waterproof briefs, I put an extra pad in the briefs so she’s well insulated, that’s the number 1 job.”

Interview 6 was with a husband alone, who was self-referred. The interview took place at his office; he told me he continues part time work as respite from caregiving. He and his wife have been married over 50 years and have five children. Two of the children live close by, a son next-door (with whom he works) and a daughter who is retired. The two children are directly involved in care giving with him. Three children live out of town and visit occasionally. He has researched Alzheimer’s disease and talks in terms of stages and cycles. His wife is incontinent and last spoke months ago. He says that his situation is what he has been dealt in life, and in life, “You play the cards you’re dealt.” He says, “...I’m proud that we can keep her at home and we are giving her the best life she can get.”

Phenomenological Analysis of the Data

The goal of this phenomenological analysis was to take the recorded interviews that are rich in personal and meaningful details and find an abstracted generalization. This

abstracted generalization captures the underlying relationships of elements with a common description that tells the reader the “whatness” or “aboutness” of the “thing,” despite the obvious disparateness of experience across the interviews. These things with our subjective *whatness* or *about which* are what Husserl (1900/2001) and Giorgi (2009) refer to as intentional objects.

I transcribed the interviews verbatim, and then imported these transcriptions into the program, SuperHyperQual as six separate data streams. I listened to each interview multiple times after the transcription and then reread the transcripts in order to linger and dwell in the data and get a sense of the whole (Giorgi, 2009). I wanted to become fluent with the language and stories given to me in order to be more sensitive and efficient with the analysis—able to keep in mind the whole while probing the supporting units of meaning.

All of the volunteers were emotional during the interviews, tearing intermittently and sighing frequently. These couples have been married 30 to 64 years—decades of learning what each other is feeling and thinking to the point they could finish each other’s sentences prior to the development of dementia.

There were obvious differences in the stories including the degree of centrality the wife’s dementia had to the story. In Interview 1, dementia was almost an afterthought for the husband. I considered eliminating this interview as not representative of the phenomenon, but decided that since the husband acknowledged fitting the inclusion criteria, and he chose to diminish dementia in his story, then this was a variant of the experience. Because there were so many commonalities in the story, I decided to include the interview. I discuss this in more detail in chapter 5.

While interviewing the participants, I was struck by their generosity in taking the time from their obviously busy lives to meet with me to share such poignant experience. General themes emerged during the interviews and became more distinct after multiple replays and reading of the transcripts.

Although all respondents reported a gradual change in their wives they were able to identify a particular point when things changed. “She got sick a short time after her mother passed away” (Interview 5). “The first time I ever noticed that [she] had a problem was back in 2007. We were in [Europe]. I noticed she told some people we were having lunch with the same story twice” (Interview 2),

The changes in their wives lead to a relationship and life refocused on the disease and PWD because of both a self-centering movement of the wife as her outside interests and social interactions narrow, and the enormity of time and work involved in the care. “She used to be very active, in fact for about ten years she worked as a volunteer over at [name of] hospice, she loved that, she can’t do that anymore so she remains fixated on her instead of things around her ...” (Interview 4). Is it work? You bet, 24/7, yeah it is. But we are bound and determined to keep her home, make her as comfortable as we can and give her the medication, take her to the doctor do whatever” (Interview 6).

There is a loss of companionship as a result of the wife’s diminishing ability to maintain the roles of their earlier relationship. There is a struggle in the adaptation to the changing conditions, the wives wanting to maintain their roles and the husbands needing to get things done: “... I think it bothers her ... I do certain things I don't mean to, just like we send every one of our grandkids their children and wives 50 dollars for their birthdays, and she's done that and I've had to start doing that and it makes her feel, you know, not, well like

I'll do that, but you have to get it done by certain days and I just know she feels like, well he doesn't think I can do that" (Interview 3).

The wives become self-isolating, less social and fear abandonment by their husbands: "She got the idea I didn't love her anymore, so she thought sure enough that I was trying to get rid of her. Nothing was further from the truth" (Interview 1). The combination of work load and difficulty communicating and understanding their wives leads to self-doubt among the husbands: "I don't feel like I've done a really good job but I feel like I've tried and we, we don't have many cross words." (Interview 3) "...so it you know just kind of wears on you, after a while, wish you could be doing something that made more of a difference" (Interview 4).

Among the many losses are those related to plans they had for their retirement and "golden" years: "I'm unhappy because of the, there are things we should be doing but we're not, mainly travel of course if she was well I wouldn't have 100% of the burden and at my age ... it's not going to get any better" (Interview 5).

These are men, ages late 70s to 80s, whose own physical health and abilities impacted care: "At 79 you're just not as active as you used to be and I can't lift her, presently she's weighing about 120 she's dead weight I can't do it (Interview six). The husbands also described expression of love in the personal care: "...so I take the same care of her teeth as I do of mine I really brush it thoroughly and I floss. I can't give her mouth wash, she'll swallow it" (Interview 5).

The husbands are proud they are meeting their responsibility: "...well it was a real drain on my energy, yet I felt she, we'd been together so long I owed that to her..." (Interview one). They have little faith in care facilities:

We were primary caregivers for her mother...and she did end up in a nursing home before she died...She had several sisters here at the time they would take turns go up there every day to help feed her...and she had great frustration about how the nursing home was being run (Interview 4).

In accordance with Giorgi's (2009) method, once a sufficient amount of time was spent listening and reviewing the recordings and transcripts and a getting a feel for general themes, I began breaking the narrative into *meaning units*, which are smaller parts, phrases, or sentences that conveyed a shared theme or intention (Giorgi, 2009). This makes the data more manageable for analysis. Investigating meaning units requires transformation of the verbatim transcription of the experience verbatim (data) to language more revealing of the sense (intentionality, subjectivity, and meaning) of the experience. This required some judgment calls on my part. The interviews were open-ended with little direction after asking, "Tell me your story."

Some of the data, on the surface, seemed irrelevant to the phenomenon of caregiving/receiving with respect to a wife with dementia. Most notable in this regard was Interview 5.

We traveled extensively for 30 years. Well you're from the East coast. Have you ever met anybody that took the freighter from north Sidney, Nova Scotia to Newfoundland? We did, we drove our car onto the you have to make reservations it's an ocean-going freighter, we stayed there for a week and then left Nova Scotia, it's a province of Canada and went back to Sidney. Seven days a week they allow, and they put on 30, 40 trailers every trip. They allow no cabs on the ship. They have to pick the trailers up on the other end with cabs, it's a fascinating trip. I've only met one

other person that made that trip. You have to make reservations, they fill up. Why that one ship is a lifeline of Newfoundland everything they produce they want to send to the mainland goes out on that ship. I tell you a funny story about the ship. We landed I don't remember the port, but when we drove back on the ship they washed the car and I said isn't that nice. New Brunswick and Newfoundland island have the best potatoes in the world but they had a potato plague that they don't want to carry over to the mainland so they wash everything that comes on board the trucks and the cars that go on in Newfoundland they wash top and bottom, we did that together and our son was with us and something on that particular trip we rented a car in Connecticut, we flew to Connecticut, we took the train. For fun we rented a car we had the car for three weeks and the rental shop was fit to be tied, we put 6,000 miles on the car in 3 weeks. And he was very upset because he lost a lot of money on the rental they lose money with the mileage. I said you wanted me to pick up the car and drive to a hotel and stay at the conference for three weeks then drive back to the airport you wanted me to put 10 miles on the car. We've done things we've been from New Foundland to Victoria, Have you taken the ferryboat from Seattle? Have you been to the San Juan Islands in Seattle Harbor?

Some authors (Giorgi, 1985) review their transcripts for data irrelevant to the experience of the phenomena under study in order to eliminate those parts before analysis. I chose to consider everything said meaningful. I considered the previous passage to be a single meaning unit from a husband who especially seemed to enjoy the opportunity to talk. I considered everything he said to be potentially relevant to their experience.

Once the meaning units were determined I arranged the meaning units for each interview above a table constructed in order to allow for easier following of the steps of analysis. (Figure 4.1) Moving from left to right I have the results of the imaginative variations and transformation as I interpret the psychological sense of the data. The first column represents a restatement from first to third person. This is important in order to begin the process of generalization. The details and facts of the lived experience can represent the same psychological meaning. It is this generic psychological set of meanings and interrelationships that the shared meaning must represent in a description, which is the finding of a phenomenological analysis.

As the transformations move to the right (see Table 4.1.), I documented my perceptions and interpretations of the statement with regard to the entire experience. I became imaginatively present in the situation as lived by each husband and used specific examples to assume the phenomenological position in their place. I also tapped my own experience and familiarity of working with PWD to go through a multitude of possible meanings. It is from this perspective that I consider the horizons of associated experience as expressed by them in order to move to a psychological understanding of what it meant for the husband to express their experience in a particular manner. For the travel description from Interview 5 recounted above, my transformation was, “Reminiscence gives context to his current experience and some comfort.” I also considered the tone of the interview when transforming meaning units and the final description. This was a lonely man who was with his wife 24 hours a day. They had this history of traveling together, but she no longer communicates and he likes to talk and share the history of their lives. The details and facts lead to the underlying psychological emotions and motivations.

The following is another example of the focus on intentionality. This is a verbatim transcription of a meaning unit from Interview 2, followed by a table depicting transformation of the meaning unit to a more generalized structure.

And so things were declining so I wrote to her doctor and asked her to recommend a neurologist which she did and went to see the neurologist who said well let's cut to the chase and got a neuropsychologist to do a study, went to see Dr. _____ who gave her some tests and said her memory, her short term memory was poor and she said that can't get a definitive diagnosis of Alzheimer's unless on autopsy, and we weren't ready for that (they both laugh). So she said it sure looked like it was leaning towards Alzheimer's so we went back to the neurologist and he increased her Namenda and she gets along fine with that and ah has it made a difference? I don't know I can't really tell. Ah she gets along pretty well at the time we met with the neurologist, that was November he suggested that she quit driving, which she has.

Y contacted their physician as he was noticing a continued decline and requested a neurology referral. Neurology referred to neuropsychology where a battery of tests were conducted, concluding probable Alzheimer's. This was conveyed to their PCP who increased the medication. Y doesn't think it has made a difference.	Y requested referral and his wife was evaluated by neuropsychology that led to a presumptive diagnosis of Alzheimer's. Her medication was increased although he doesn't notice a difference. His wife has quit driving at their recommendation.	Decline led to more medical intervention and a clearer diagnosis.
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Figure 4.1. Transformation of a Meaning Unit

The final column shown in Figure 4.1 becomes the basis for the subsequent description of the structure of the experience. Once the last transformations were assembled

on the same pages, these pages were reviewed multiple times, compared to the text of the interview, and rewritten into a more coherent, less linear description of each man's experience with a separate paragraph for the wife's experience as relayed by the husband, and the wife participant in Interview 2. In the above example the last column had not yet gotten to the underlying structure; it was more a distillation of fact. Further transformations moved the data further from the life world experience towards the psychological underpinnings of the phrases. The following is the final transformation of this volunteer's experience incorporated several meaning units:

After decades of companionship and shared experiences, he worried about his wife when she told the same story twice to the same people. He thought it was strange enough and out of character to take her for a professional evaluation, which led to a diagnosis of dementia that left them stunned even though they were expecting it. He never imagined this situation, if anything he thought it might be her caring for him. He is glad they had all the time they've had together, that this has come after retirement. The situation gets old, stale, but he has no regrets. He wishes she didn't have this, but it isn't a negative. He is sad and contradicts himself. He remembers how they both laughed when they were told the only definitive diagnosis was on autopsy. They find humor in their situation; it is a way of maintaining an emotional connection, he is there keeping her company.

The last transformations of the six sets of meaning units were read and compared until the common sense of the phenomenon could be derived from the data. The descriptions were revised, compared to the interviews to assure representation, and modified again through an iterative process until through this imaginative variation and consideration of a

range of meanings, the inter relation of sensations, feelings, emotions and judgments—was brought out from the text in order to answer the following research questions:

1. What is the meaning of dementia to husbands caring for their wives with dementia?
2. What is the meaning of dementia to wives receiving care from their husbands?

Structure of the Experience

The “structure of the experience” identifies the elements and their interrelationships, which are essential to say that particular phenomena took place. The character of the phenomenon was more discrete in works Giorgi (2009) referenced than in my research. Giorgi’s involved recollections of a particular incidence of the phenomenon, for example a memory of an incident leading to a feeling of jealousy or of a pivotal moment in one’s psychotherapy. My study involved a holistic accumulation of many small moments of the entire experience, which would be the experience of grief while caring for a wife with dementia, as opposed to the more discrete. Though recollections are not static, the consciousness of an experience over time is much more fluid and hologrammatic than recollections of a single incidence of a phenomenon more easily depicted with a flow chart. Within the structure I have used to present experiences uniquely lived, each experience has variants that exist within a range of the same psychological structure. I discuss this further in chapter 5 under the section, Interpretation and Synthesis, in which I also suggest some models to represent the phenomenon. I have chosen to present the following descriptions in the third-person voice for each of the interviews and then the composite, generic experience because it presents the experience in a way that the meanings and their interrelationships can be more efficiently felt and shared. The meaning unit transformations and revisions of structure are in Appendix H.

Individual psychological structures

Interview 1. He is still grieving for his wife who died months ago from a combination of problems he still doesn't understand. He feels guilt, even now he wonders if he could have done better, were there things he missed? He thinks he did the best he could; he tries to believe that. For the last years, he had been struggling with care giving for his wife as a result of her debilitating problems.

He found it especially difficult responding to his wife's irrationality. He knew she didn't make sense, but he still tried to reason with her, a situation that led to frustration and anger on both their parts. She couldn't control her body or her mind, it seemed like someone else was in there. He couldn't control her when she was abusive and belligerent; he would respond belligerently, but he felt like he should be able to figure out what to say or do to keep her calm. He relied on medical and psychiatric professionals who did not provide practical help—it did not help with day-to-day getting along. There were so many appointments, mostly unsatisfactory interactions. They couldn't seem to fix her. Many medications and medication changes didn't seem to make much difference.

It seemed the more he asked for help the less substantial help he got. He felt chaos between short periods of calm. His life became unpredictable and focused on his wife, her behaviors and her general decline. When she was diagnosed with dementia it didn't seem important.

They had to move closer to medical care because he couldn't manage the distances to health care providers. As his wife declined and did less of what she used to do, he found himself doing more, which seemed to aggravate and scare her because it pointed out her declining ability.

She retired early in order to enjoy the rest of her life. But over time she lost interest in her previous activities as well as her surroundings. She would call out or refuse care unpredictably as expressions of frustration and anger. They had decades of shared experience, now just the two of them isolated, no friends or family nearby. No children.

He could not communicate with his wife, she seemed irrational and angry, and at the same time she was afraid he would abandon her. He could not understand what she was going through. He felt ineffective—when he tried to help she would snap at him, and sometimes he would snap back. He didn't feel like any of his efforts were making a difference. It seemed she was in and out of hospitals, yet her condition got worse. His wife needed his help for mobility, hygiene and nutrition. She needed him to lift her and turn her when she couldn't do it herself. He struggled with this; she was too heavy. The care giving was non-stop, round the clock care and watching, vigilance. He did not like this, he was angry at having to do this, especially because they had home care, but his wife's belligerence drove them away. He felt he should not have to be doing all the work, but he did make a commitment, "for better or worse." But still he was tired of the lonely hard work. He was in charge of their lives together. Still he held onto hope and expected improvement. When his hope for improvement waned he would feel desolate and loss for their lives together and any interesting future. He felt he should be able to keep her interested in living.

She reached out to random people, as well as spiritual counselors, grasping for a connection with anyone other than her husband. She knew and was distressed about her decline; she understood the implications of becoming dependent on her husband—she knew she wouldn't recover. She was frightened. When she became wheelchair bound she felt she

would never get better. She did not want to live the way she was. She couldn't control her body or her mind and gave up.

He struggled with his sense of commitment to their long relationship and the difficulty of all-day care. He thought his efforts were a way of demonstrating love; he did not think she recognized it as such. He wanted her to be more grateful because by her responses she did not recognize his efforts and he was trying hard, doing his best to take care of her. He would reminisce; call on earlier memories to keep the situation in context but there seemed to be a paucity of good memories. He was relieved when his wife was hospitalized over the last months. He felt hopeless and helpless while experiencing her continued decline that forced him into the caregiver role. He was stuck.

Interview 2. He worried about his wife's mind. He thought it was strange enough and out of character to take her to her for professional assessment, which led to a diagnosis of dementia that left them both stunned. He never imagined this situation, if anything he thought it might be her caring for him. He is glad they had all the time they've had together, that this has come after retirement. He wants to hold onto what they still have as long as possible. He hopes the decline is slow and gradual. The situation gets old, stale, but he has no regrets. He wishes she didn't have this, but it isn't a negative. He is sad and contradicts himself. He remembers how they both laughed when they were told the only definitive diagnosis was on autopsy. They find humor in their situation; it is a way of maintaining an emotional connection, he is there keeping her company.

He sees changes in his wife that are significant, distressing and he isn't sure if it is medication or disease, he would find a logical explanation reassuring. He watches her personality change, she is more dependent, wants him nearby. She feels her independence

diminishing. He is forced into controlling more of her day-to-day life. He is constantly vigilant, unable to leave her alone for any length of time because he is worried, not sure where the debility begins. He has to repeat his same answers to her same questions. This aggravates him, particularly because he knows she has no control over it, “it” being the disease, which makes him feel angry, then sad and guilty about his response. She has this thing; this disease that has no cure that has become the non-remitting focus of their lives.

She is aware her husband is making up for her deficits. She knows she has problems thinking but is unable to say exactly what they are. She tries to maintain feelings of normalcy by diminishing these changes. She takes her time to compose sentences, organize her thoughts. She is self-conscious and protective of possible slip-ups. She doesn't want to sound stupid. She grieves for her loss but is unsure what exactly she has lost.

He has gradually taken on more daily responsibilities as his wife becomes unable to continue them. There was no point where he made a decision to be caregiver, it happened. They are ambivalent about treatment in the context of a situation they know will get worse. Though he knows his wife's identity/ personality is changing, he doesn't know what to expect as time passes, he has read, is familiar with possible stages, this gives some tentative sense of preparedness. He feels a sense of powerlessness with the understanding of inevitable decline, unsure of his ability to manage the situation. He is lonely. He feels the loss of his wife's companionship. He is frustrated by the situation sometimes feeling resentful—she doesn't try hard enough. He misses the person she used to be. He cries when he thinks of that woman.

She no longer knows where things are. Her husband gives her direction; she can't do anything without his awareness, permission, like a parent. She looks at him for confirmation

of what she says. She is unable to remember what is different; she listens to her husband's version and restates it. She feels she is not as essential as she used to be. She used to handle everything. She jokes about her husband leaving her if, when, she needs help with bodily functions. She is afraid that maybe he will abandon her.

Interview 3. He and his wife have shared experiences of challenges and successes for decades. He feels old and close to the end of their lives. When they retired they wanted to be closer to their children and medical care. Since a stroke, she has struggled physically and mentally; she is unable to stand for any length of time and can't keep up with what she used to do, but needs to keep doing it. He knows that she really hates and resents becoming dependent because she was always independent and seemed to be able to manage anything. He knows she is aware of her memory and thinking ability failing, and this hurts him to think she may be feeling less of herself. He knows she has dementia but this is a horrible thing and a nasty word, it leads to depersonalization and a sense of being flawed, he doesn't want his wife to feel flawed.

She used to like company and entertaining, but now prefers isolation. She is persistent and stubborn, she wants to walk without help, continue her previous routines by herself. This adds to his struggle of care giving for him because certain things have to be done at certain times and waiting for her to do them doesn't work. Her time line isn't linear. She forgets what he has told her, and then she gets angry accusing him of having no trust in her. She is frustrated, resisting acceptance of the situation. She has withdrawn more from social interaction and needs physical representations of security. She wants to feel she has control over her life. She is unable to conduct life activities that she enjoyed in the past. She can't do anything alone, without help, she is trapped.

He tries to identify her mental states to achieve some insight into her needs, the way she used to think. He needs to keep her comfortable, reasonably happy. At times he is torn between responsibilities of the outer world and his wife's changing inner world. Supporting his wife's ongoing assertion of her independence makes life more difficult for him. Even tasks like feeding become battles of oppression/ control and resistance. He can no longer rely on her support and insight, because his wife's emotional behavior and view of the world is different. She is delusional and gets angry for reasons he can't understand. Sometimes he is shocked at how differently she sees things. He is learning new patterns of communication to avoid her wrath and maintain his responsibilities—he manages, handles her. He loves her more, feels closer and tries harder but feels ineffective in making any headway communicating with her and sharing their long established companionship.

He has learned to manage the physical care but the emotional upheavals and personality changes are almost unbearable. He is sad and cries. They want to support and be with each other until the end of their lives. Regardless of his care giving struggles and how she responds, he knows his wife loves him as he loves her and he is grateful for their wonderful lives.

Interview 4. After years of marriage and shared experiences, his wife became confused not knowing where she was. He was scared and took her to the hospital where she was treated but never quite returned to normal. Shortly after that she was diagnosed with dementia and their lives changed. From that point on their lives became focused on his wife and her condition.

He manages his wife's medications and appointments. She never seems really well. He knows her prognosis is poor; he is grieving because treatment at best slows down

progression towards total incapacitation and death. He has become parental, looking out for her health and safety.

Her condition fluctuates, sometimes almost her normal self, but it is unpredictable and he can never relax. He plows sluggishly through days consisting of the same routines and tasks. He never knows what she will say or how she will act or what she may want. She is irrational at times and acts upon delusions. She is unpredictable. He thinks this is fairly typical of the disease, some assurance there, in a known pattern. She must always be supervised. He must be vigilant all the time because he can't trust her to be safe without supervision. Her contradictory demands make her impossible to please and communication extremely difficult. She is not the woman she used to be. Loss of companionship and the sameness of day to day living are hard for him. They have less and less meaningful interaction; their routines have become restricted to the custodial.

She seems to sleep all the time. He feels alone in their house, thinking about their shared life that went on there. He is lonely. His days consist of a series of emotionally and physically demanding tasks that don't seem to make a difference to his wife's wellbeing. When she lacks energy or interest it is more difficult for him to get through the day. He has to manage her daily activities, make her get up, make her eat. Feeding has become a power struggle, they negotiate a meal then she refuses to eat it. He knows she can't help it but he can't stop thinking that really she can and is being contrary—resisting in order to assert a self, which is disappearing. There is a day-to-day drudgery of sameness in the completion of care giving tasks that seems to stretch time out, slow it down. He feels the loss of their planned future—they were going to travel, they can't do that anymore. He is stuck.

If he thinks of his wife as the woman she used to be he would be no help to her in the present situation, he has to become impersonal and immune to her emotional fluctuations to be efficient.

There is a delicate balance to the current situation and support relationships. He is afraid to introduce new helpers; more people would confuse his wife. He wants more help but fears her negative reaction. But when the helper is there, he gets to leave the house, free for a little while to do what he wants.

As his wife has withdrawn socially he has engaged with others in his situation and sought dementia resources for education; with this support he doesn't feel the need to diminish the experience. He can be honest, sometimes even laugh with other people taking care of someone with dementia. There's some reassurance that her experience fits a known pattern of dementia that he has read about.

She usually lacks interest in her surroundings or activities, is withdrawn and sleeps later in the mornings and takes frequent naps. Sometimes she needs to be bathed and toileted. She used to enjoy life and have many interests, now she is like a different person, focused on herself, physical aches that migrate and change daily. She is fixated on her body and demands his attention. She is irritated when her husband is around and anxious when he isn't. She asks permission for almost anything she wants to do. But that isn't much; her husband does everything. She enjoys visitors, her daughters, who give her a break from him. She is frantic with her sense of being a burden, yet hounds him with repetitious complaints and demands. At times she is afraid he might want to divorce her; other times she demands to be dropped off at a nursing home. He should forget about her. Every once in a while she just wants to die.

The thought of institutionalization makes him cry. It would be like abandoning her to impersonal strangers. Over time he has become a full time caregiver, there was no conscious decision; as her abilities have declined his responsibilities have increased. He had no choice. He is proud of what he is doing for her, just very sad watching her become someone barely recognizable. His wife is gone. He has no regrets. He wishes he could do something that made more of a difference.

Interview 5. He was surprised when his wife told him she could no longer manage a routine role in their relationship and turned the task over to him. Gradually she was able to do less and he had to do more. Now she is dependent on him for everything, and it is so hard because she doesn't talk. She walks, holding his hand and following. The situation is medically ambiguous which frustrates him because the diagnosis offers little in the way of treatment and the prognosis is poor, which he has a hard time accepting. He doesn't believe they really know what's wrong with her. He feels dementia has been marginalized by other social and medical priorities because of ignorance and irresponsibility. He has given up searching for a medical cure. He sees medical care as experimental anyway, no clear benefit from medications. When his wife's medical providers encourage his involvement in her care he feels more control over the situation.

He is also feeling his age, slowing down, feeling the loss of the expected retirement life while he props up his wife's existence. He had expected to be enjoying life and traveling, but is unable due to the current set of circumstances. He grieves for the loss of a projected future and his wife's companionship. He finds it hard and lonely dealing with someone who doesn't communicate. His life has become focused on her. Ultimately he is proud of what he is doing for his wife.

He continues activities the way they used to, going everywhere together without respite. He socializes, with her at his side watching. He reminisces about their life and travels together before their lives changed. This reminiscence gives context and comfort to his current situation. He remembers specific trips vividly wants to share all the details, enjoys talking if someone will listen.

He projects his wife's emotional responses. She has almost disappeared in his story except in terms of tasks related to her care. He finds hope in minor changes in her attentiveness. He is proud of the way he grooms her, cares for her body. He doesn't talk to her very much, just gives directives.

He is committed to his wife and knows he is doing a better job than a nursing home would, where he feels the care is inadequate and impersonal. He remains hopeful and confident that his effort has value to his wife. He is imagining the future but has not researched options. He lives with the uncertainty of the situation. He is unhappy with the entire situation but sees no alternatives.

Interview 6. He is an elderly man with recent medical problems that had him concerned about his longevity. He has gradually become caregiver to his wife who is now in a wheelchair and under his control. His children assist in this care that is all day all the time, basically the same physically demanding routine that is drudgery and boring. This has become the focus of their lives. There is no end in sight, so they maintain their course with humor and a positive attitude as tools against such poor prognosis. He grieves for the loss of who she used to be. They schedule respite breaks aware that ongoing care requires that they stay healthy. She depends on him.

He accepts this responsibility as part of life and his moral obligation. He would never abandon his wife to impersonal institutions that provide poor care. He doesn't trust outsiders who were unable to provide the care they way his family does.

He feels indebted to his wife for years of companionship. At times he refers to her as part of "they"—meaning the demented. This characterization helped him deal with her irrational behavior by removing it and seeing it as different from her. He wavers between thinking his wife may be completely unaware and believing that her affect and ability to feel their love is intact. He and his children care for the spirit of who she used to be, maintaining long-term family routines she used to enjoy. He reminisces remembering her spirited approach to life, which helps bolster his day-to-day efforts. He amplifies any indications that his wife's old self is there. Every now and then, he thinks she recognizes him.

She has been through "stages" he understands through his reading, including behaviors that presented difficulties being in public. They had to insulate her from this. He found this isolating and illustrated the general ignorance of the population regarding dementia. He felt validated and less isolated when able to address some of this ignorance, as well as when his situation was understood and admired by his peers. She hasn't spoken in weeks, but soon they will be going to a place they've been going to for years. He is sure she will feel or remember something. He is proud of what he is doing.

General psychological structure of the experience. These are the elements common to all six couples interviewed.

They have been companions for decades managing events and stressors in their relationship together. They have shared memories and experiences. They have established a reciprocity and balance to their relationship that is now unbalancing. He can identify a point

when the change in circumstances occurred. Ever since, he has been increasingly wary of his wife's behavior, her conversation, and physical condition—on the look-out for aberrations. He hears the lapses, her pauses, as she thinks. She is not quite herself. His own health is failing to some degree. Physical work is harder than it used to be. She is changing into a different person, more demanding, more needy, and he has to take up the slack. He gradually becomes the caregiver because they are living together.

She feels the changes but can't say what exactly they are. The familiar becomes foreign; there are way too many choices; she can't figure out sequences or order. She can't follow conversations when there are too many people, or too much talk. She needs more time to process what has been said. She is afraid of being found out. She has dementia, it will get worse—he will have to change her he will want to leave her.

There is no outright declaration of decision, but he feels obligated because of their shared history, his feeling of commitment. Somewhere along the line names or diagnosis are given to characterize the change, so she now, officially, has no control or volition regarding these changes that have focused their lives on her and the condition. He considers these diagnoses in his assessment of the situation, the more applicable, the more comforting that the situation is a known one with storied stages, the less applicable the less useful in devising strategy. Though there may be periods of slight improvement the trajectory is degeneration and death, which is inevitable anyway. He has to make up for her deficits and he does this by taking on household responsibilities he never had before. He wavers between being confident that he is fulfilling his duty and responsibility and to some degree, resentment at the unfairness of the situation for both of them. He feels guilty when he is resentful. Overall he is proud of what he is doing.

She has vague memories of being efficient, now her husband watches her with a critical eye, looking for defects, almost always there giving her permission for one thing or another. If he isn't there she looks for him. She stops in the middle of sentences to find a word. Her vocabulary is shrinking. There are longer pauses between sentences, she says the same thing over again, does not want to be asked anything.

As time goes on he is caring more for a body and less for a person. This begins with concerns for safety and controlling the environment, social as well as physical, and extends to dressing, hygiene, toileting, and feeding her body. Reminiscing about their good times can fuel his efforts because who she is now maybe irrational, frustrated, and belligerent. Communication diminishes. He becomes stuck in a situation that won't get any better, and for the most part feels like he isn't providing much benefit. He still hopes that she can get more comfortable, less angry, more responsive, more like she used to be or that some cure will be found, but in general this hope is tempered by the grueling day-to-day effort of caring for his wife who has dementia. He hopes she knows what he is doing for her, that she can appreciate the love it conveys. When he thinks about nursing homes he thinks institutional care—impersonal, inadequate.

She no longer goes out without her husband or chaperone of some sort. Her husband manages their lives. She has nothing to do, her husband does. She sees the sadness and concern in his eyes. She wants to be home where she's safe. If they go out she can hold onto him, follow along and let him do all the talking and interacting. He is a buffer against the outer world, he fills in the gaps. She is afraid that she has lost herself.

Summary

This chapter presents the changes I made to the original protocol, stories from the study volunteers, and an outline of the analysis process to give sense and context to the study findings. Phenomenological research holds the experience apart from the routine natural attitude of the life world in order to study human consciousness. The dyads in this study co-created their experience. The couples were emotionally engaged after decades of marriage and had established a balance and reciprocity that was disrupted by events and responses related to dementia. The pre-dementia dynamic cannot be restored due to the wife's decline, so the husband struggles with empathetic projections to provide his wife with what she can no longer express or do. This gradually becomes custodial care and maintenance of the wife's personhood. The dynamic changes in a vortex of time and energy narrow the couple's interaction with the outside world and focus their lives on their shared struggles. Many factors influence feelings of success, guilt, grief, and weariness. Husbands display their love and commitment and meet their sense of responsibility by keeping their wives out of institutional care; they choose a positive attitude and feel blessed.

Chapter 5 presents the implications of these findings by revisiting the discussion of existential loss and Edith Stein's theory of inter-subjectivity that was presented in chapter 2. The third research question, what do the findings mean to nursing as a field is discussed in the context of nursing theory, practice, and the existing literature. Recommendations for further research are presented as well.

Chapter 5

Interpretation of the Findings

The findings in this chapter are presented in the development of a representative model. I discuss the analysis of the findings in response to, “What is the meaning of dementia spousal care giving/care receiving with respect to nursing care?” and in the context of existing research literature, theory, and practice. This is followed by reflections on method and considerations for further research.

The Meaning of the Husband/Wife Experience for Nursing

Synthesis and situation within the nursing literature. Caregiving can be an opportunity to develop personal meaning through the compassion and empathy required in caring for another (e.g., Farran et al., 1991; Farran, et al., 1999). Farran et al. (1999) suggested that provisional meanings develop into ultimate meaning in an existential sense, as in “choosing a positive outlook” or “drawing upon personal fortitude.” Though researchers (e.g., Carbonneau et al., 2010; McLennon et al., 2011) have investigated global or existential meaning, phenomenology asserts that consciousness is the production of meaning as connections between judgments, perceptions and so forth, lead to interpretations made in response to objects that enter our experience.

As noted in Chapter 2, Piiparinen and Whitlach (2011) considered “existential loss” to be the psychological state of caregivers who encounter multiple losses as their partners decline and the focus of their own lives significantly changes. Piiparinen and Whitlach conceptualized this as a process of interplay between the deep (intuitive, symbolic) and surface (self-focused, situational) mind.

I also suggested in Chapter 2 that, with regard to dementia, Edith’s Stein’s focus on the thetic character of the act of consciousness would bring about a better understanding of the caregiving experience of the couple (e.g., Sawicki’s field of *Is* as a representation of

Edith Stein's view of consciousness and empathy). The way we interact in the world and our stream of consciousness involve personal and physical aspects with degrees of variation; shareable only through the sensate and mental experience that also exist with degrees of variation and are not distinctly different regions of consciousness.

These four aspects of consciousness are conspicuously changing within the tangled dynamic lived by wives with dementia and their caregiver husbands. Husbands feel pride in the care and situation they have accomplished in their negotiation of meanings and needs expressed by their wives. This pride is suffused with doubt about the effectiveness of their caregiving, as well as resentment that this is what they were doing with their retirement years, and then guilt about having those feelings. Preservation of their wives' personhood seemed to distract them from their own self-maintenance, leading to problems with loneliness and isolation and feelings of being stuck. As the husbands' perspective moved away from themselves toward their dyadic identity, their empathy deepened. Through maintenance of their wives' personhood they found sparks of hope against the inevitability of decline, but also frustration with the drudgery and isolation of caregiving. There were very poignant expressions of love creating a sense of pride, which feeds back into doubt and a more tangled web of emotion. This is not simply cyclical because the empathy deepens and the interactions between self and other, family, community, healthcare practitioners, and is in constant changing flux.

The reciprocity and empathy developed through years of shared experiences in the pre-morbid relationship of the couples now exists with the effects of the wife's dementia. This limits her ability to share her awareness and his ability to intervene when behaviors and actions are unintelligible. Her sense of self, independence and communicative ability

diminishes. The long shared sensate and mental interfaces of empathy are blocked by the cognitive changes impeding communication in that manner. This leads to his attempts to meet her through the physical and personal aspects of consciousness considered privileged areas of the self (Stein, 1989).

The husbands are able to access these assumed-to-be-privileged aspects of their wife's self through recollection of shared sensate and mental contents of the past, and projection of these contents onto the ways of behavior in the present (i.e., what they said, what they liked to eat, listen to, and how they enjoyed themselves) in order to understand and provide care that sustains their wife's personhood.

The husband interprets his wife's physical and verbal expressions in the context of their social and cultural situation, the meanings of dementia not as a socio-political construct in their world as I originally proposed, but through the more immediate inter-subjectivity of consciousness. As a result, the husbands' "I" becomes superimposed on the increasingly frail structure of the wives' "I", demonstrating a unique example of empathy—human experience constituted by "the other." Figure 5.1 is a visual depiction of this process.

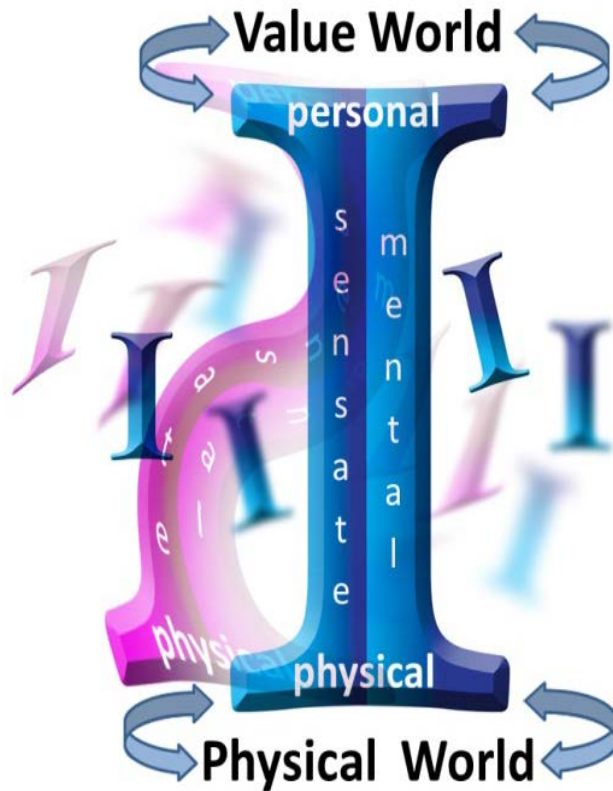


Figure 5.1 The Consciousness of Husbands Caring for Wives with Dementia

Recommendations for Further Research

Descriptive phenomenological study findings are not “themes” as commonly portrayed in other forms of qualitative research. They comprise an independent, general psychological description, as a phenomenological reduction of individual life experiences expressed through participants’ natural attitude. Some issues the volunteers raised and their individual stories have value to nursing practice and healthcare in general.

The Inter-subjectivity of Caregiver/Care Receiver

The findings of this research clearly describe the inter-subjective nature of the participant’s lived experience and supports Stein’s view that empathy is a pre-condition for consciousness. The powerful empathy developed between husbands and wives suggests that

any interventions aimed at assisting husband caregivers should include the care recipient, and those addressing the wife with dementia should include the husband. At the present time, outcome research is sparse and inconsistent. Interventions and approaches reported in the literature include the use of marriage biographies (Davies & Gregory, 2007) or approaching spousal dementia caregiving as expressions of “couplehood” (Helstrum, Nolan, & Lundh, 2005, 2007) to capture the complicity as well as complexity of the lived experience. This perspective also supports interventions such as the “Alzheimer’s Café” and modifications of it (Morrissey, 2006), as well as reminiscence groups REMCare (Woods et al., 2012). These programs address quality of life for the PWD and caregiver stress.

The Resources for Enhancing Alzheimer's Caregiver Health project (REACH) is one of the longest intervention research studies and includes information, instruction, role-playing, stress management techniques and telephone contact. It has been found to improve aspects of caregiver burden such as depression, health and healthy behaviors, caregiving frustrations, social support, dementia-related behaviors, and time spent providing care (Nichols et al., 2011)

Personhood. Several studies were cited in the literature review describing participation of PWD beyond early, mild cognitive changes (cf. Gillies, 2000; Langdon, Eagle, & Warner, 2007, Phinney, Chaudry, & O’Connor, 2007). Therefore, in the original proposal both husbands and wives’ responses to their caregiver/ recipient situation were to be collected by interview. In the completed study, only one wife who was able to express herself to a limited extent was enrolled. Though she was ambulatory and capable of self-care, she was unable to participate fully in the interview. She was unable to provide any perspective regarding assessment of her responses to what dementia has been like for her,

other than expressing a sense of feeling less essential as she became responsible for less around the house and in the relationship. For the most part, I was unable to really engage her in deep reflection or discussion, leaving the husband to relay her experience.

She did not demonstrate any problems with distractibility or misunderstanding of questions, she just seemed to be left blank. She was unable to make before and after diagnosis comparisons due to the reality of cognitive impairment. When her husband prompted her memory, she basically used his cues and repeated what he said. Nevertheless, from her responses it was evident that her affective sense of self (e.g., her sense of humor and emotional expression) was fully engaged and intact. She had looked forward to the interview, as related by her husband, by asking him several times that morning when they would be leaving to meet with me.

Accessing the affective aspect is difficult, but its importance is unmistakable. This finding holds an important implication for research. In contrast to the present study, the approach of Clare et al. (2008) in their study of awareness among PWDs with moderate-to-severe dementia was less formal than mine. Their respondents who lived in long-term care facilities were engaged in multiple short conversations over a period of days, during their daily routines. Their conversations followed their respondents' lead, ending and resuming from four to 15 times for the 80 participants. This enabled the researchers to assess interest in engaging and participating. Remington (2002) found 10 minutes of calming music and hand massage lessened agitation for up to an hour after the activity. Other multisensory stimulation interventions (Collier et al., 2010) have been used with varying degrees of success. Bubble tubes, optic fibers, music, scents have been used to reduce agitation, improve engagement with others, and attentiveness to surroundings (Cruz et al., 2011). In

terms of eliciting data for phenomenological research, multiple engagements, as in Clare et al. (2008) with PWDs following multisensory stimulation, might render more useable expressions of experience and meaning by promoting a quieter mind more able to articulate or at least less distracted.

The second implication with respect to personhood is that interventions addressing PWDs should involve more affective aspects. Practitioners should make the effort to learn their patients' life stories including education, interests, history and family.

They should understand that, due to the cognitive decline, communication through tone of voice, touch, and patience become paramount in caregiving and share that with informal caregivers.

Intimacy. Although intimacy in terms of inter-subjectivity is clearly part of the phenomenal description developed by the study, the sexual part of the marital relationship and any post morbid changes to it were not mentioned in any of the interviews. My questions were broad allowing the participants to relate experience in their own way. Sexuality is a very private and personal subject to most people and I believe if I had asked about it, or had subsequent interviews participants would have offered insight into this area of human being.

Ballard et al. (1999) found that over 25% of the couples in their study with mild to moderate dementia self-reported continued mutually satisfactory sexual relations. Davies, Sridhar, Newkirk, Beaudreau, and O'Hara (2012) found that most PWDs (72%) initiated some type of physical intimacy and were able to stay engaged, and this did not differ by gender. Harris, Adams, Zubatsky, and White (2011) found that high self-reported levels of intimacy pre-morbidity continued after diagnosis and assumption of care by the spouse and

ameliorated caregiver stress. Practitioners should offer an opportunity for dementia caregiver/receiver couples to talk about this aspect of their lives or make appropriate referrals to those who can explore this area tactfully and with respect.

Decisional capacity. Decisional capacity relates to preservation of personhood, but it also enters the ethical domain. In this study husbands gradually became the voice for their wives, as they were less able to manage different aspects of daily living on their own. The tool I used for determining decisional capacity, Evaluation to Sign Consent (Resnick et al., 2007), is a five-item screen determining ability to communicate, to explain the purpose, and potential risks of the study as well as to acknowledge the need to report and discontinue the study if that is what they want to do.

The implication from the descriptive results of this study is that affective capacity continues beyond that of the cognitive and is ingrained in the subjective and emotional being of the person. This must be considered when determining decisional capacity. If a person screams and holds up her hands in defense, it probably means no. and that should be respected regardless of the intensity of the dementia. Decisional capacity should be considered relative to the situation, not generalized as all or none. In addition the importance of completing advance directives cannot be over emphasized.

Stage theories. Although the findings of this study were consistent with themes and isolated stage descriptions cited in the literature review (chapter 2), there was no linearity. Wilson (1989) described eight stages of caregiver response: Noticing, Discounting and normalizing, Suspecting, Searching for explanations, Recasting, Taking it on, Going through it, and Turning it over. Lindgren (1993) proposed three stages: Encounter, Enduring, and Exit. Most experiences consist of an encounter, period of endurance, and decision about its

perpetuation. The data collected through volunteer interviews in this study suggests a more complicated process than what has been described in more linear fashion as occurring in stages. Imposing the abstraction of stages potentially detracts from understanding the lived experience in a phenomenological sense.

Older men as caregivers. Dementia caregiving is physically demanding. The difficulty of care increases as men develop age-related frailty and illnesses of their own. Older age, living alone with the spouse, increasing ADL needs and worsening cognition are all associated with nursing home placement (Yaffe et al., 2002). Consistent with other reports in the literature, my volunteers reported a sense of endless 24-7 work. Chenoweth and Spencer (1986) conducted a study in which 75% of respondents reported that the 24-hour nature of caregiving—having to watch their relative 24 hours a day—gradually became unmanageable and reason for institutionalization. The associated lack of sleep, chronic stress and cumulative physiological wear of this constant effort negatively impacts health of the caregivers (cited in Clark et al., 2007). This is well documented in the literature and suggests a need for PWDs and their caregivers to be followed by case management with appropriate referrals for respite care, home care assistants and adult day services.

Perceptions of nursing home quality. My study participants thought nursing homes and other forms of institutional care were impersonal and inadequate. They were proud that their caregiving kept their wives at home. Delaying nursing home placement is considered a benefit as far as overall healthcare costs, as well as for the quality of life (QoL) of the PWD. For example, much of the research into interventions to support PWD caregivers uses time to nursing home placement as a study end point—successful interventions delay institutionalization. This is considered to be a matter of QoL as well as money. Unpaid

caregivers for ADRDs provide 80% of community care, which, if paid, is estimated at \$216 billion a year. Nursing home costs average \$222 per day for a semi private room (Alzheimer's Facts and Figures, 2013).

Because the incidence of ADRDs increases with age and we have an aging baby boomer population, estimates for the prevalence of dementia are increasing. The latest Alzheimer's Facts and Figures (2013) estimates a 50% increase in incidence of ADRDs in the West and South between 2000 and 2050 (59% for New Mexico). This will have a substantial impact on health care spending. Any way to delay institutionalizing adults with AD potentially represents savings in overall societal health care costs.

Other than the enormous financial impact, there are some advantages to nursing home care. There is wide range of nursing home quality. They offer socialization through individual and group activities, opportunity for medical care on site, and potential for physical, occupational, and speech therapy. Many nursing homes have specific programs for people with dementia. Although subjective measures of quality of life (QoL) of PWDs are difficult to assess (Crespo, Hornillos, & Gomez, 2013), some evidence suggests that self-reports of QoL by PWDs are more reliable than staff or family reports (Moyle & O'Dwyer, 2012). This suggests the need to balance the laudable desire to maintain PWDs at home and independent as long as possible with the recognition that long term care may be beneficial in some respects.

Standards of care in nursing homes have changed in the last decade. Many incorporate patient-centered interventions based one individualized plans of care (Brownie & Nancarrow, 2013). The changes also have created new paradigms for nursing homes. For example, the Eden Alternative (2013) claims that loneliness, helplessness, and boredom are

the basis of suffering in nursing homes and among the elderly in general. The Eden Alternative proposes to combat this by providing an environment closer to nature, and by revising the traditional administrative structure (Brownie & Nancarrow, 2013). Such facilities have easier access to the outside, including gardens and companion animals, and are less regimented and intent on a medical focus.

Studies of these new types of programs are very limited. Early studies suggest facilities that fully engage in the program have reports of more falls (Chenoweth et al., 2009). However, they also have increased patient-reported QoL and family satisfaction (Roshier & Robinson, 2005). Through socialization and programming, the isolation and loneliness of the PWD/ caregiver can be addressed. This is an area for continued research. The original intent of this research was to investigate the experience of couples at the time they were considering day services. Understanding the situation among couples during this transition is important. Study of strategies for effective integration of PWDs from home into nursing homes is also essential.

Reflections on Method

This study covers a broader experience and perspective than originally proposed which is pertinent when considering Giorgi's methodology developed for more discrete experiences. The findings demonstrate the utility of this method for developing understanding of a broader lived experience. This study supports findings of similar studies and adds to the growing literature on the dyadic experience of caregiving and receiving during the course of dementia and, at root, the nature of human empathy.

The daily struggles of these couples are heroic, particularly at a time in our history when individual wants and needs seem to be emphasized more than sacrifice and service to

others. The cohort for the study represents the generation before the baby boomers. Their social context includes the Great Depression and World War II, when divorce was still somewhat stigmatized and extended family living arrangements were the norm. Who among us has the fortitude to carry on in the manner these couples have? Volunteer three told me, “I love her. I’ll say that I love her more now than ever before and I think vice versa and we thank the Lord for that great family that is ours and we feel pretty happy and pretty responsible.” How will baby boomers deal with caring for each other as they age? Would the structure of their experience be the same as these findings?

Consider the original assumptions of this phenomenological method:

1. The structure of another’s pre-reflective consciousness can be studied by elicitation of narrative descriptions from experiencing participants.
2. Everything we know originates from the privileged first-person experience.
3. Results of phenomenological research can be generalized.
4. Our access to objectivity is through inter-subjective constitution.
5. Human consciousness shares common structure, though how it is layered is personal.

Review of Assumptions and Discussion of Limitations

Regarding assumption one, the pre-reflective state of consciousness is the natural attitude, naïve to analysis of the phenomena. Is there such a thing as a pre-reflective state among men caring for wives with dementia? As soon as changes in their wives’ behavior become apparent, the period of pre-reflection is gone. To some degree, senses are heightened as the husbands become vigilant in looking for more incidents of the change in wife category, until a new category, dementia, is substituted. This requires some reflection.

To identify one's self as the caregiver of a wife with dementia means that many more reflections already have taken place.

I am not sure I can say that I studied another's pre-reflective consciousness by analysis of narrative descriptions from experiencing participants. I did engage my privileged first-person experience to analyze data from others' first-person privileged experiences in order to access an objective description of inter-subjective constitution. I stood in the place of my volunteers and, through analysis of their narratives, arrived at a general description of what is meant by caregiving to a wife with dementia, which supports assumptions two and four.

I am skeptical of the state of pre-reflection. Just asking for an account of an experience can shift one from the natural attitude toward phenomenological analysis. Shim, Barraso, Gillis, and Davis (2013) distributed flyers to recruit for their study, looking for caregivers who self-identified as having found meaning in their care of a spouse who had been diagnosed with dementia. One of the caregivers admitted that the thought that caregiving could be meaningful had occurred to him only when listening to a short recruitment speech at a support group meeting.

Any thoughts put into language are no longer pre-reflective to the extent they have been organized into speech. However, reflection and analysis exist on a spectrum. Phenomenological analysis is deeper and more rigid than what occurs when organizing ideas into thought; it is meta-analysis.

This is the critical piece to Giorgi's (2007) objections to member checking as insurance of rigor. Although we reflect and organize thoughts into speech, the type of

phenomenological reductions required by this method may well lead to findings unrecognizable to those contributing the natural attitude of the experience.

Assumptions two and four are straightforward. Our own consciousness meets with other consciousness in order to negotiate meanings as phenomena appear to us. Through negotiation of facts and forms of the physical world we come to some kind of agreement about what is.

Assumptions three and five are probably the most controversial. In the literature review and methods discussion, I described the nature of phenomenological research and controversies in the nursing literature regarding the range of rigor and theory within the different research approaches. Although interpretive phenomenological research may be “a poetizing activity” (van Manen, 2007, p. 13), descriptive phenomenology is not. It is descriptive—not interpretive and not theory building. My description is interpretive because that is the nature of consciousness: objects come into our consciousness and we make sense of them. Bronowski (1956), the noted mathematician and poet said, “Science is nothing else than the search to discover unity in the wild variety in nature or more exactly, in the variety of our experience. Poetry, painting, the arts are the same search...” It is incidental that Saldana and Adorno found Picasso’s transformation of a bull to represent the phenomenological process. Art values investigating the identity and purpose of human being (Sullivan, 2010). Scarry (1999) describes art in the beauty of poetry as being bound up with the immortal, “...for it prompts a search for a precedent, which in turn prompts a search for a still earlier precedent, and the mind keeps tripping backward until it at last reaches something that has no precedent, which very well may be the immortal,” (p.30).

Physiological accounts of neuro-fibrillary tangles or memory access in the hippocampus are also descriptions, but ones that leave qualia—those intrinsic features of subjectivity—out of the picture. Phenomenological research resides within the category of qualitative research. Denzin and Lincoln (2005) describe many uses and meanings of different methodological traditions in qualitative research, complicating any actual, distinct definitions. However, a concern with the subjective is at the root of most qualitative approaches. It seemed to me that the rich details of the qualia of individual lives were so expressive in themselves that transforming them into a generic experience was disrespectful. Volunteer six says, “... she made a comment, ‘something’s wrong with my head and I can’t explain it’.” “I sleep with one eye open.”

By choosing the phenomenological method I was committed to search for the shared structure, which required shifting away from the facts of experience as expressed in the natural attitude. This presented a paradox: In the facts of the experience lie the generalities; the specific images convey the universal. We are left with some uncertainty.

Once a phenomenon is chosen, the fact that it is considered a phenomenon means a generalization has already taken place. For example, spousal abuse or relinquishment of care is outside the phenomenal boundaries of caregiving. This is the heart of the argument for generalizability. Although individual, deeply lived life experience is a result of unique qualia, subjective awareness is responsive to general aspects of the phenomenon and the intersubjectivity of experience in general. Meanings are built on shared memories that continue to be incorporated as new experiences become memories.

There are constants among husbands caring for wives with dementia. The husbands are older men who have shared decades of life with their wives. This includes some shared

sense of cause and effect and a shared sense of the patterns in the world. The wife has an identified change that will continue to erode her ability to make sense of life's patterns. He has to respond in some way. The course is progressive, so the work gets more difficult. The "generalizability" of phenomenology can be understood as shared experience of structures and meanings, rather than the generalizability of quantitative research and statistical analysis, which looks for inferences, averages and population projections. Invariant essences are the set of circumstances required in order to call the phenomenon a phenomenon.

A possible threat to this assumption of generalizability is gender differences in consciousness. I chose men as caregivers and women as care receivers so as not to enter the realm of gender differences in consciousness. My literature review includes research that suggests there are gender differences in approaches to caregiving, as well as experiences of burden and development of related allostatic load. Though the structure retains its integrity across gender differences—the way objects enter consciousness is the same—I chose to study male caregivers as opposed to females to avoid issues regarding gender-ness of consciousness.

Another possible risk involves sociocultural or ethnic differences. I did not ask the couples cultural background questions. From the stories and appearances, volunteers appeared to be middle to upper-middle class socioeconomically, and all were White. At least seven of the eight participants indicated that they were college educated and two had advanced degrees. Whether variations would occur with a more varied sample remains unknown.

Sun, Ong, and Burnette (2012) reviewed studies of Chinese-American dementia caregivers who lived in three different U.S. urban coastal cities. Two significant themes

dominated their findings. The first theme was the way caregivers understood dementia; in early manifestation it was considered a normal variant of aging, a return to a child-like state. As the dementia progressed it was perceived as a mental illness and stigma. The second theme was the role of traditional values in prescribing parent and child behavior. Adult children have responsibilities to parents who have reciprocal responsibilities to their children, which become difficult to fulfill when living with the effects of dementia. According to the authors, this leads to feelings of shame and disgrace. They did not differentiate by gender or caregiver relationship in their review. The caregivers are more likely to be the children. Although the structure of the experience would be the same, the context of the structure is different.

In a study conducted in mainland China (Chan et al., 2010), researchers found caregiving to be as challenging as my descriptive findings suggest, citing “confusion about diagnosis,” “emotional impact” “difficulty in coping with recipient’s behavior,” “provision of care recipient’s daily care needs is demanding,” and “conflicts among social roles” as pervasive themes in caregivers’ responses (five of the 27 respondents were husbands). One of the husbands in the study said, “I am so ambivalent and distressed...I think it’s too cruel to send her to a nursing home. I feel guilty towards her and blame myself for having such thoughts...I find it too exhausting to look after her....” (p. 165). These sentiments echo my results.

Italian researchers identified six themes by phenomenological analysis: changes in relationships, changes in lifestyle, difficulties in caring, hopes and fears for the future, family duty, and respectful treatment (Vellone, Sansone, & Cohen, 2002). Although expressed

differently, the essence is the same. None of the studies noted here was specific to caregiver gender or relationship.

The method of data collection also can potentially influence the responses. The data for the analysis depends upon the accuracy of the stories the couples share. It is possible that I was able to arrive at a general psychological structure because of societal scripts that lead to stereotypical responses—in effect, volunteers telling me what they think they should be feeling. Another possible limitation is within the set of men willing to tell their stories. The untold stories may have different structure, though given the variables of the situation that is not likely. Another possible limitation of the study is researcher bias. I have left an audit trail by providing all transformations from the initial transcription to the final psychological description. There were times during this process that I struggled over words, for example, the difference between feeling “trapped” and “stuck.” After much deliberation and review of the transcripts, I chose “stuck” which seemed to better capture the sense of entropy and inertia, compared to “trapped” which seemed to suggest lack of choice or powerlessness in the matter.

Another example of researcher bias is general conclusions for information I did not understand. From Interview 3:

...she just isn't (comfortable). She's, she just, you know. And we invite a friend to come and have dinner with us, she'll do it and I do it, but it's just harder on her to accept that sort of thing. And in the past you know we've had lots of people, lots of things going on and, and she's. . . it's tough for her now and it, you know, I, I love her more. I've tried harder, but it's a tough job and comes the oxen at the same time.

I was not familiar with the idiomatic expression, “comes the oxen at the same time,” and when I asked for clarification he said:

Well you’re not, I’m never; I cook the kind of stuff I like, like ranch and Mexican food. After I retired I did a lot of canning just for fun and, but I don’t, it’s hard to make up menus to come up with stuff she would like and she was a picky eater.

I was still unsure of his meaning, but he seemed to be telling me that one difficulty was bad enough without another one being superimposed. An intermediate transformation of that meaning unit became: “It is tough enough to be the caregiver. It is even harder to watch the woman I have known and loved change so dramatically, to the point that previous enjoyments are avoided.”

Conclusions

Dementia is a progressive, neurodegenerative condition that follows a course of gradual cognitive decline and increasing dependence. The majority of those who have dementia live at home and are cared for by family members. Caregivers to PWD are affected psychologically, socially, and physically. A minority of this group are husband caregivers who are elderly and often have chronic problems of their own.

This study investigated the lived experience of married couples facing dementia, through interviews and phenomenological analysis. The findings of the study are a description of the interplay between husband and wife as the wife became more dependent and began, in essence, losing herself while her husband rallied to his perceived responsibilities in the situation. Empathy is strengthened through the long- term relationship allowing the husbands to compensate later in life for the wives loss of empathic expression.

The title “Bound and Determined,” was chosen from interview data because it represents part of the essence of the experience of these men. The connotations of “bound” include the bonds of matrimony as well as the state of being determined and resolved, as well as bounding and being constrained—all part of the dynamic expressed by the volunteers in this study. The expression of these essences are found in the words of volunteer six, the meaning of caregiving/care receiving by husbands and wives with dementia:

We have a cabin on the Canadian border, but just on a crazy whim she's in a wheelchair so I said to the kids lets go for a boat ride, so we lift her in the wheelchair into the boat to go for a boat ride, daughter [daughter's name] has got a Speedo and she's running next to us and [wife's name] says "Is this as fast as this thing can go?" And I'm just busting up laughing because even though she's incapacitated in a wheelchair, she's a good old shoe, got in the boat with us. And that was her comment. So, when you bust your tail 24/7 and some people make a comment like that, it's worth it. Trust me, it's worth it. You just gotta laugh. It's funny. It's hard at the cabin. I don't know that she recognizes the wildlife we have up there—the cabin sits 20 feet from the water—we have birds and deer and bear. I'm not really sure she recognizes. She's past that stage...we've been doing this for so long with the wheelchair . . .7, 8, 9 years. We're going to the cabin in 6 weeks and if there's a recollection? She doesn't resist—4-hour plane ride, drive to the cabin, stay in a motel. Yeah, I think she enjoys every minute. She wouldn't tell you that because she can't, but she loved the cabin and she never wanted to go home. She'd want to stay another day. I think that's there, all the kids are around her, she likes that so we'll keep doing it. That's what we'll do. I think there's some recollection to it.

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Appendix A: Husband's Consent Form

The University of New Mexico Health Sciences Center Consent to Participate in Research The Lived Experience of Dementia: Husbands Caring for Their Wives

Introduction

You are being asked to participate in a research study that is being done by Jennifer Averill, RN, PhD, who is the Principal Investigator, and Melanie Mayo, RN, FNP-BC, PhD-c, from the Department of Nursing who will be using the information for a doctoral dissertation.

This research is studying the way a wife's dementia is experienced by married couples.

Most people with Alzheimer's-type dementia are living at home, cared for by family members. Studies have shown that this can be very stressful as well as rewarding. Much of these feelings of stress and reward result from the way the couples make sense of the experience as a team.

You are being asked to participate in this study because you are a husband wanting to share your life experience on audio or videotape. You have been married at least 20 years. You are a couple in which the wife has been diagnosed with dementia at or after age 70. You speak English. You are able to see and hear me. A maximum of 10 couples will take part in this study.

This form will explain the research study, and will also explain the possible risks as well as the possible benefits to you. We encourage you to talk with your family and friends before you decide to take part in this research study. If you have any questions, please ask one of the study investigators.

What will happen if I decide to participate?

If you agree to participate, the following things will happen:

I will contact you and answer any questions you may have. If you continue to want to participate we will set up appointments for audio or video recorded interviews and determine the location, in your home or a private space in an agreed upon public facility like a school or library, first with you, the husband, your wife is welcome to sit with us through the interview. If she does, her signature will be required and your signature for her, if she is unable to understand the purpose of the interview as determined by a screening for decisional capacity. These interviews will last approximately ½–1 ½ hours. I will ask general questions such as, "Tell me how dementia entered your life," "What kind of care do you provide?" "What is important to know about you and your life right now?" There are no right answers; I want to hear your story. Your wife will be welcomed to make comments during the interview. If possible and not necessarily, a second interview may take place with the wife, husband sitting in, 1–10 days after the initial interview also last a maximum of 1 ½ hours.

How long will I be in this study?

Participation in this study will take a maximum of 1 1/2 hours on one or two days depending on your preference.

What are the risks or side effects of being in this study?

There are risks of stress, emotional distress, inconvenience and possible loss of privacy and confidentiality associated with participating in a research study.

For more information about risks and side effects, ask the investigator.

What are the benefits to being in this study?

Information gained from this study will contribute to the greater understanding of the impact of dementia on married couples, which may help professional caregivers improve their services.

What other choices do I have if I do not want to be in this study?

You do not have to participate.

How will my information be kept confidential?

We will take measures to protect the security of all your personal information, but we cannot guarantee confidentiality of all study data.

Information contained in your study records is used by study staff and, in some cases it will be shared with the sponsor of the study. The University of New Mexico Health Sciences Center Human Research Review Committee (HRRC) that oversees human subject research, and the Food and Drug Administration and/or other entities may be permitted to access your records. There may be times when we are required by law to share your information. Your name will not be used in any published reports about this study.

Consent forms and identifying information will be kept in a locked drawer in Dr. Averill's office for approximately 18 months. Audio or videotapes will be transcribed; these transcripts will not have your names on them. When the project is completed, within 18 months, this information will be shredded. Videotape will be viewed only by the research team and will be erased following completion of the project.

What are the costs of taking part in this study?

Your time and energy.

What will happen if I am injured or become sick because I took part in this study?

It is unlikely you will be injured in any way because of an interview. The following information is generally provided for any study. If you are injured or become sick as a result of this study, UNMHSC will provide you with emergency treatment, at your cost.

No commitment is made by the University of New Mexico Health Sciences Center (UNMHSC) to provide free medical care or money for injuries to participants in this study.

In the event that you have an injury or illness that is caused by your participation in this study, reimbursement for all related costs of care will be sought from your insurer, managed care plan, or other benefits program. If you do not have insurance, you may be responsible for these costs. You will also be responsible for any associated co-payments or deductibles required by your insurance.

It is important for you to tell the investigator immediately if you have been injured or become sick because of taking part in this study. If you have any questions about these issues, or believe that you have been treated carelessly in the study, please contact the Human Research Review Committee (HRRC) at the University of New Mexico Health Sciences Center, Albuquerque, New Mexico 87131, (505) 272-1129 for more information.

Will I be paid for taking part in this study?

No.

Can I stop being in the study once I begin?

Your participation in this study is completely voluntary. You have the right to choose not to participate or to withdraw your participation at any point in this study without affecting your future health care or other services to which you are entitled.

Whom can I call with questions or complaints about this study?

If you have any questions, concerns or complaints at any time about the research study, Melanie Mayo, or her associates will be glad to answer them at (505) 235-5396, or you may email Melanie at MMayo@salud.unm.edu.

If you would like to speak with someone other than the research team, you may call the UNMHSC HRRC at (505) 272-1129.

Whom can I call with questions about my rights as a research participant?

If you have questions regarding your rights as a research participant, you may call the UNMHSC HRRC at (505) 272-1129. The HRRC is a group of people from UNM and the community who provide independent oversight of safety and ethical issues related to research involving human participants. For more information, you may also access the HRRC website at <http://hsc.unm.edu/som/research/hrrc/>

CONSENT

You are making a decision whether to participate in this study. Your signature below indicates that you read the information provided (or the information was read to you/). By signing this consent form, you are not waiving any of your legal rights as a research participant.

I have had an opportunity to ask questions and all questions have been answered to my satisfaction. By signing this consent form, I agree to participate in this study with audio tape/ videotape (circle one). A copy of this consent form will be provided to you.

Name of (print) husband

Signature of Husband Date_____

If wife is present:
Signature of
Wife

Printed name of wife:

Date_____

Capacity Screening requires husband's
signature:

INVESTIGATOR SIGNATURE

I have explained the research to the participant and answered all of his/her questions. I believe that he/she understands the information described in this consent form and freely consents to participate.

Melanie Mayo

Name of Investigator/ Research Team Member (type or print)

(Signature of Investigator/ Research Team Member) Date

Appendix B: Wife's Consent Form

The University of New Mexico Health Sciences Center Consent to Participate in Research The Lived Experience of Dementia: Husbands Caring for Their Wives

1/20/13

Introduction

You are being asked to participate in a research study that is being done by Jennifer Averill, RN, PhD, who is the Principal Investigator and Melanie Mayo, RN, FNP-BC, PhD-c, from the Department of Nursing who will be using the information for a doctoral dissertation. This research is studying the way a wife's dementia is experienced by married couples.

Most people with Alzheimer's type dementia are living at home cared for by family members. Studies have shown that this can be very stressful as well as rewarding. Much of these feelings of stress and reward result from the way the couples make sense of the experience as a team.

You are being asked to participate in this study because you are a husband wanting to share your life experience on audio or videotape. You have been married at least 20 years. You are a couple in which the wife has been diagnosed with dementia at or after age 70. You speak English. You are able to see and hear me. A maximum of 10 couples will take part in this study.

This form will explain the research study, and will also explain the possible risks as well as the possible benefits to you. We encourage you to talk with your family and friends before you decide to take part in this research study. If you have any questions, please ask one of the study investigators.

What will happen if I decide to participate?

If you agree to participate, the following things will happen:

I will contact you and answer any questions you may have. If you continue to want to participate we will set up appointments for audio or videotaped interviews and determine the location, in your home or a private space in an agreed upon public facility like a school or library, first with you, the husband, your wife is welcome to sit with us through the interview. If she does her signature will be required and your signature for her, if she is unable to understand the purpose of the interview as determined by a screening for decisional capacity. These interviews will last approximately ½- 1 ½ hours. I will ask general questions such as, "Tell me how dementia entered your life," "What kind of care do you provide?" "What is important to know about you and your life right now?" There are no right answers; I want to hear your story. Your wife will be welcomed to make comments during the interview. If possible and not necessarily, a second interview may take place with the wife, husband sitting in, 1-10 days after the initial interview also last a maximum of 1 ½ hours.

How long will I be in this study?

Participation in this study will take a maximum of 1 1/2 hours on one or two days, depending on your preference.

What are the risks or side effects of being in this study?

There are risks of stress, emotional distress, inconvenience and possible loss of privacy and confidentiality associated with participating in a research study.

For more information about risks and side effects, ask the investigator.

What are the benefits to being in this study?

Information gained from this study will contribute to the greater understanding of the impact of dementia on married couples, which may help professional caregivers improve their services.

What other choices do I have if I do not want to be in this study?

You do not have to participate.

How will my information be kept confidential?

We will take measures to protect the security of all your personal information, but we cannot guarantee confidentiality of all study data.

Information contained in your study records is used by study staff and, in some cases it will be shared with the sponsor of the study. The University of New Mexico Health Sciences Center Human Research Review Committee (HRRC) that oversees human subject research, and the Food and Drug Administration and/or other entities may be permitted to access your records. There may be times when we are required by law to share your information. Your name will not be used in any published reports about this study.

Consent forms and identifying information will be kept in a locked drawer in Dr. Averill's office for approximately 18 months. Audio or videotapes will be transcribed; these transcripts will not have your names on them. When the project is completed, within 18 months, this information will be shredded. Videotape will be viewed only by the research team and will be erased following completion of the project.

What are the costs of taking part in this study?

Your time and energy.

What will happen if I am injured or become sick because I took part in this study?

It is unlikely you will be injured in any way because of an interview. The following information is provided in general, for any study. If you are injured or become sick as a result of this study, UNMHSC will provide you with emergency treatment, at your cost.

No commitment is made by the University of New Mexico Health Sciences Center (UNMHSC) to provide free medical care or money for injuries to participants in this study.

In the event that you have an injury or illness that is caused by your participation in this study, reimbursement for all related costs of care will be sought from your insurer, managed care plan, or other benefits program. If you do not have insurance, you may be responsible for these costs. You will also be responsible for any associated co-payments or deductibles required by your insurance.

It is important for you to tell the investigator immediately if you have been injured or become sick because of taking part in this study. If you have any questions about these issues, or believe that you have been treated carelessly in the study, please contact the Human Research Review Committee (HRRC) at the University of New Mexico Health Sciences Center, Albuquerque, New Mexico 87131, (505) 272-1129 for more information.

Will I be paid for taking part in this study?

No.

Can I stop being in the study once I begin?

Your participation in this study is completely voluntary. You have the right to choose not to participate or to withdraw your participation at any point in this study without affecting your future health care or other services to which you are entitled.

Whom can I call with questions or complaints about this study?

If you have any questions, concerns or complaints at any time about the research study, Melanie Mayo, or her associates will be glad to answer them at (505) 235-5396, or you may email Melanie at MMayo@salud.unm.edu.

If you would like to speak with someone other than the research team, you may call the UNMHSC HRRC at (505) 272-1129.

Whom can I call with questions about my rights as a research participant?

If you have questions regarding your rights as a research participant, you may call the UNMHSC HRRC at (505) 272-1129. The HRRC is a group of people from UNM and the community who provide independent oversight of safety and ethical issues related to research involving human participants. For more information, you may also access the HRRC website at <http://hsc.unm.edu/som/research/hrrc/>.

CONSENT

You are making a decision whether to participate in this study. Your signature below indicates that you read the information provided (or the information was read to you/). By signing this consent form, you are not waiving any of your legal rights as a research participant.

I have had an opportunity to ask questions and all questions have been answered to my satisfaction. By signing this consent form, I agree to participate in this study with audio tape/ videotape (circle one). A copy of this consent form will be provided to you.

Name of (print) husband

Signature of Husband Date_____

If wife is present:

Signature of Wife

Printed name of wife:

Date_____

Capacity Screening requires husband's signature:

INVESTIGATOR SIGNATURE

I have explained the research to the participant and answered all of his/her questions. I believe that he/she understands the information described in this consent form and freely consents to participate.

Melanie Mayo

Name of Investigator/ Research Team Member (type or print)

(Signature of Investigator/ Research Team Member) Date

Appendix C: Evaluation to Sign a Consent Form for Research

Name: _____

Date of birth: _____

Direction:

Ask the patient questions 1 through 5. The evaluator may select the appropriate language to use in formulating the questions in order to assist the subject's understanding.

Items

1. What is the purpose of this study, what am I studying?

2. Will any of the procedures be painful?

3. Will you benefit in any direct way by participating?

4. If you don't participate in this study, how will your regular medical treatment change?

5. Once you agree to participate will you be able to change your mind?

I hereby certify that the above patient is alert, able to communicate and able to give acceptable answers to items 1- 5 above.

Evaluator/ Date _____

Appendix D: Recruitment Flyer

University of New Mexico College of Nursing
Volunteers wanted for PhD research study:
The Lived Experience of Dementia:
Husbands Caring for Wives

Are you a Husband who is currently, or has in the past year, been caring for a wife with dementia?

My name is Melanie Mayo, and I am a nurse practitioner and doctoral candidate at University of New Mexico College of Nursing. I want to learn how health providers, like me, can best help other couples going through what you and your wife have been experiencing. I am looking for couples together at least 20 years with a wife diagnosed with dementia at or after the age of 70. I would like to interview the couple if possible or the husband alone, for as long as you would like to talk.

(Estimate ½-1 ½ hours, 1-2 interviews). All interviews will be kept confidential.

If you would like to tell me the way it is, call me at (505) 235-5396, for further details. I want to listen.

Study # 12-472. If you would like to speak to someone other than the research team call Human Research Protections Office: (505)-272-1129

This research is being conducted under the direction of Principal Investigator Jennifer Averill, RN, PhD, Associate Professor of Nursing.

Appendix E: General Outline and Script for Interview

I will begin the interview by thanking the participant for participating and remind them the focus of my interest is their experience of dementia.

Mr./Mrs. [Name], as you recall, my name is Melanie Mayo and I am doing research into the way couples experience dementia.

Examples of possible questions for the husband include:

What stories can you tell me?

Would you give me examples of how your wife is experiencing dementia?

What kind of care do you provide?

What kind of help do you need?

What is important to know about you?

Examples of questions for the wives include:

What stories can you tell me?

What is it like being cared for by your husband?

What kind of help do you need?

What is important to know about you?

I will use probes to elicit more detail:

Please tell me more about that.

Would you give me an example?

Do you remember how you felt when that happened?

Would you elaborate?

Appendix F: Recruitment Letter to Colleagues

Melanie Mayo, RN, FNP-BC, PhD-c

7608 Harwood Ave. NE
Albuquerque, NM 87110
(505) 235-5396
January 22, 2013

Dear (insert name of colleague),

I am a doctoral candidate at University of New Mexico Health Science Center researching dementia from the perspective of couples—men caring for wives who have developed senile dementia. This letter is actually a follow up to a previous letter in which I requested help with the recruitment of volunteers. In the time that has passed since I began this study, I have gained a lot of feedback and in accordance with this information I have filed a modification of the original protocol. I found that I was asking too much in the way of time and intimacy by asking to videotape in people's homes. I found that I had narrowed the inclusion criteria to the point that it excluded many people who were otherwise eager to share stories of what their lives are like. I also found that many of the caregivers are protective of their wives and would prefer not to expose them to any possible embarrassment by asking them to talk about their own dementia. After reflecting on my own experience trying to access this population I admire and want to help, I have changed my inclusion criteria.

I am now looking for men caring for wives with a dementia diagnosed or has developed when the women were 70 years or older. The men should have been married to or long term companions of the women for at least 20 years and either are currently caring for their wives or have been within the last year. I will audiotape or videotape, whichever is most comfortable for the volunteers. I ask for ½ to 1-½ hours of time for the interview. I would like to interview both husband and wife, but will be happy to interview the husband only. I have some general questions to begin the interview but mostly I will follow their lead to what the experience is like, what their struggles and triumphs are and what they think is most important for healthcare providers to know about what their lives have been like at the day-to-day level.

If you are aware or become aware of any couples in your practice meeting these criteria, would you please give them one of the enclosed flyers? I appreciate any assistance you can offer.

Sincerely,

Melanie Mayo

Appendix G: Inclusion Criteria

Wives:

- 1) Age 70 and older with a reported medical diagnosis of senile dementia. YES___ NO___

Husbands:

- 1) Married to and/or living with the person with dementia, at least 20 years, now, or within last year providing care. YES___ NO___

For Both Groups:

- 1) The ability and interest in participating in an audio or videotaped interview. YES___
NO___
- 2) English speaking
- 3) Able to hear me.

Names of couple: _____

Preferred location of interview: _____

Phone number: _____

Appendix H: Meaning Units and Structures for Interviews 1–6

Interview 1

So this is March 20th and we are beginning the interview. So I gave you a little background, are there any stories or how do you want to start?

Well my Mrs. S. passed away on July 3rd of last year, she passed away from a pneumonia, stroke or say pneumonia and stroke—combination thereof, she had a problem with bipolar and that kind of worked against her for the last 10 years.

His wife died last year from a combination of medical problems. She had a bipolar disorder that significantly affected the last 10 years of her life.	Although his wife died from a medical condition her bipolar disorder played a major part in her decline.	There was a ten year decline resulting from the psychological disorder.
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Anyhow she, they first discovered it in 1993. I took her to the hospital one evening and she was acting erratic, belligerent, wanting to throw things, stuff like that so I took her to the ER and ah Doctor said, well at that time the hospital was Rehoboth McKinley General in Gallup they had a what do you call it, a behavioral health unit which they later got rid of because they couldn't find the professional help and they were sending most everybody to Albuquerque or Farmington, anyhow they kept her overnight there and the doctor on duty couldn't figure out what was going on they ran blood tests and all that stuff, and um couldn't figure out what was going on. Well there was a nurse who happened to be on that unit and she had taken some courses over here at UNM she spotted it immediately she said I know what's going on its a class I went to in Albuquerque she's got a bipolar problem, well that was new to the doctor I guess he hadn't heard of that sort of thing though apparently it was common then although I had never heard of it before then, this was 1993, anyhow they kept her a week kept her a week a couple weeks over here in a unit called I think Park Hospital it was over here in the Journal square area at that time, after that they released her because they had given her a number of meds, a protocol, and it looked like those were working, so they released her with the idea she got to go home but she had to come back once a month to talk to a psychiatrist.

<p>The bipolar problem was discovered in 1993. Following a belligerent aggressive event Mr. X took his wife to the ER for evaluation where she was kept overnight because the physician on duty could not diagnose the problem despite multiple diagnostic tests. A nurse on duty was able to identify the problem having recently taken a course at a university. Mrs. X was transferred to a psychiatric hospital and released when stable on medications, and scheduled weekly visits with a psychiatrist.</p>	<p>X became aware of the bipolar problem when an erratic, belligerent behavioral episode prompted an ER visit. She was kept in-patient on the behavioral health unit until stable on medications and then released with weekly psychiatric follow up.</p>	<p>A specific event 20 years ago identified a background psychological problem as well as a history of unsatisfactory interactions with both medical and behavioral professionals.</p>
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Well we did that and for the next about 13 years things were fine. They got the meds were the right level, and so things were fine. Things looked great. I thought maybe, oh boy, we have this thing solved./

<p>For the next 13 years things were stable, the medical providers had the medications right, and Mr. X reports things looked great.</p>	<p>Mrs. X remained stable on the medications, Mr. X was optimistic for the next 13 years.</p>	<p>The background problem was stable for years.</p>
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Well we lived a good life 'til about the year 2-0-0-6 and suddenly all this bipolar business seemed to come back. And of course part of recognizing that is, she gets very belligerent. It seems like her mind's controlling her body, what she's doing, and all that sort of thing. And it proved out she could be dangerous when left alone in situations like that, and I know that because she tried throwing things at me, knives, and golf balls, bottles of water, things like that which resulted in us calling the police and having her taken back to ER, telling them what's happening. And of course the doctor would decide what to do. She had a regular care provider at that time and the problem was he was not steeped in that mental-type problems. So my problem's living with her. So they sent her up to Farmington, the hospital up at Farmington, for about a week and they had a, what do you call, healthcare center up there and uh she stayed a week and they couldn't find anything wrong with her, so they sent her back home.

<p>It seemed to Mr. X that suddenly his wife became belligerent again which he recognized as the bipolar problem. To him it seemed there was a mind-body disconnect that left her dangerous when left alone with him. There were incidents when she was physically abusive requiring 911 calls, and being transported to the ER, where her PCP would make decisions as to care. Mr. X feels that was a problem because the PCP did not know much about his wife's illness. She was sent to another hospital for a week then released because no explanatory diagnosis was found.</p>	<p>Abruptly Mrs. X became unstable, violent and abusive which Mr. X recognized as the bipolar problem. This entailed multiple 911 calls and visits to the primary care practitioner who was not familiar with the illness so she was ultimately transferred to another facility and then released without specific findings.</p>	<p>Abruptly there was a change in his wife's behavior leading to situations where he could not get through to her—unsafe behaviors requiring hospitalization. They lived in a rural area; the PCP was unfamiliar with the diagnosis and referred his wife to a more distant facility. They did not understand his problems living with his wife.</p>	<p>His wife's thinking and behavior changed he could not relate to her rationally, he looked for a medical explanation.</p>
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Yet they had never really explored. They had never explored in depth what she was going through and the doctor, through his notes said, so they brought her back home. Part of the problem I had from then almost until the day she passed away, bipolar seems to put you in, you get very moody. You can be very happy one minute and really down another minute and it's how to cope with that and going through her. Going along with the counselors I learned a few tricks on how to control her or at least learn how to live with the fact she was having trouble mentally the fact having trouble mentally. They had tried to adjust her meds many, many times. She had a psychologist over at Gallup that she went to almost every week. And G tried to, that was the problem, maybe try this med and that med, maybe more of this less of that less of this more of this, all kinds of combinations. It was driving me nuts because I was supposed to be responsible for seeing that she took her meds on time and I couldn't keep up with all that. It was just mind boggling, what she was going through and I finally said, G., look, let's get down to something positive here because I don't think all those changes are doing J any good, and my own mind set is not happy about changing meds all the time./

Mr. X feels that his wife was inadequately assessed and her emotional experience was not addressed, that she was dismissed. Mr. X's experience of her illness was that of very labile moods. With the help of counselors he did learn some techniques for managing aggressive behaviors.	The doctors did not understand what his wife was experiencing, but Mr. X was experiencing his wife's labile moods and had to pick up tactics to manage the behaviors because the medical management was difficult and seemed slow and experimental and finally he had to challenge the care plan because it was too much for him.	The problems that he was experiencing with his wife were never sufficiently managed by the medical/psychological providers despite multiple medication changes leading to his challenging of the care plan.	He felt helpless to deal with the situation but didn't feel like the medical/psychological help was doing any good.
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Well in the meantime, we switched psychologists. Her name was G., clinical psychologist. We went to a doctor with Presbyterian Medical Services. He was an authentic psychiatrist so we switched to him. We started going to him instead, and he didn't change the meds very often, but he did want to know, every time we came, how it was affecting her one way or the other. So we got him the information he needed as time went on.

X reports that they changed providers to one with more expertise. The new psychiatrist managed and monitored medications more carefully.	X switched to a new provider who was more methodical.	A temporary delicate balance was reached.
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Ah, in the meantime, and I noticed something else at the time, seemed like in the last 2 or 3 years she was gradually slipping a bit downhill, it seems like her life itself. We had her pretty well set and fine, and she was active. Then we decided so she should be close to, ah, medical facilities, have medical help nearby, we'd sell the house, move to Albuquerque. We had traveled around, explored Albuquerque a bit and checked out retirement places and this is the one she liked and I liked it too, so We put our name on the list and this was about 3 years before they actually contacted us, that they said we may have something ready for you it was in Sept–Oct 2010 so we started, we got to the point we were downsizing, have you ever tried to the point of downsizing? That means literally you get rid of most of what you've got because literally downsizing meant moving from where we lived to an apartment like this. We rented an apartment downstairs; on the first floor when we first moved in it was the same size as this one. It was adequate for us at the time, but uh we moved in got everything fairly settled. But Mrs. S was having, what was it, um, seems like mentally she was kind of losing it./

Despite management of the bipolar illness, X reports his wife was generally declining. He felt it was prudent to move closer to medical facilities, and downsizing. They found an independent living facility	Over the next 2–3 years his wife's general health declined, so they made a decision to move to be closer to medical care.	His wife's medical condition became the focus of their lives.	The decline in his wife's health resulted in major life changes including
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connected to a long-term health care center and settled in.			moving to a retirement / independent living home.
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Memory and being out of control sometimes that was part of the thing, living here she would get angry. When she was angry nothing seemed to please her./

X describes the decline as both memory and behavior. When she got angry it was impossible to please her.	By the time they moved into their new place his wife's memory and anger were to the point he had difficulty pleasing her.	He did not know how to please her.	His wife's thinking and behavior was irrational, he could not get through to her.
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She got the idea I didn't love her anymore, so she thought sure enough that I was trying to get rid of her. Nothing was further from the truth but she spent probably as much time over in the health care center as she did here, maybe more so./

Mrs. X felt he didn't love her anymore and felt he was trying to get rid of her by sending her to the health care side of the facility, but this wasn't true.	Mrs. X had frequent admissions to the care side of their independent living facility to the point she felt he was trying to get rid of her, which was not the case.	Mrs. X misinterpreted his attempts to help her as him trying to get rid of her.	Mrs. X feared his abandonment of her.
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Plus hospital time at U and L, and they always took her to the mental health unit, behavioral health unit. Well she was having trouble keeping herself under control and she would go to the units. They would talk her down from her high or bring her up from her low. She suffered periods of deep depression plus what do you call it, where you're so high, there's a word for it—periods of mania and they blamed it on the bipolar.

X says his wife also spent time at the hospital where they would admit her to the psych unit.	In addition to the admissions to the care facility she had frequent hospital admissions related to her bipolar illness.	There were multiple hospitalizations for behavioral problems.
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As far as I could tell it would affect her thinking and her brain and uh well she sometimes would lose control, by that I mean she would get real angry if something didn't go the way she wanted it, like dishes let say dishes, let's use that as an example I'd say I'm going to do the dishes, let's say finish them. Okay that's great, but maybe I'd be slow about doing them or maybe they didn't get done. She'd get angry. "I thought you were going to do the dishes." "Well, I'm still working on them." "Not this instant." She expected things to be done right now If I said I was going to dishes or vacuum, then she expected they would get done right now and I couldn't. It was hard for me to tolerate that because I don't operate that way. As you can see I don't operate that way quite often. I guess I'm just kind of slovenly in a way.

X says his wife's thinking and brain were out of control, which often left her angry with him.	By this time her thinking was also affected, she got angry easily and he could not meet her expectations.	He had difficulty meeting her expectations that were unreasonable due to her brain dysfunction.	He tried to fill in by assuming her responsibilities but his efforts didn't meet her irrational expectations.
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Anyhow, it seemed to progress that she was losing. She had a situation that they could never put their finger on. There seemed to be a disconnect between the brain and the rest, the lower body. She had trouble walking. This got worse and worse. As time went on, she had trouble walking/

X says his wife continued to decline she was losing a battle with an illness that the medical providers could not quite diagnose. He thinks of it as a mind body disconnect, she began to have mobility problems.	X's wife continued to decline to the point she couldn't walk. X doesn't think the doctors knew exactly what was going on.	No medical help could stop the continued decline. The brain-body disconnect got worse and she became more dependent for ADLs.
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It got to the point they were taking her over here to uh physical therapy and running her through physical therapy about two three times a week, well I wish they had done it all week, uh, they were busy and not always there but they did it as often as possible but and that. /

X says his wife began physical therapy which he wishes had been more than 2 or 3 times a week, but there were staffing problems	Physical therapy was initiated, but X feels it wasn't enough.	He did not get the help he needed to restore is wife's mobility problems.	He expected improvement.
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I'm sure that worried her. It started to worry her even more because I was trying to keep her out of a wheelchair. I was trying to keep her walking with the aid of a walker, but it got to the point she couldn't even use her legs. I tried to stand her up get her to move around. She would stand up, balance, and she would just fall over. There was a severe balance problem and then she wasn't active moving her legs. So it got to the point where everywhere I took her, I had to use a wheelchair and that was the thing I tried to keep her out of. And then of course, it gradually came to the point she was bedridden because, so, she could sit on the edge of the bed, but she couldn't move around and as time went on, she started having trouble with dressing and undressing and going to the bathroom./

X knows his wife was aware of her decline and worried since his major effort was to keep her mobile and out of the wheelchair. But eventually she developed problems with balance and mobility and was bedridden. This progressed to inability to dress and toilet herself.	X knows that his wife was worried and aware of her decline. He tried hard to maintain her mobility but ultimately she declined to the point he had to help with dressing and toileting.	His wife was worried and aware of her decline as her husband began total care for mobility and hygiene.	His wife was aware and distressed about her decline.
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So at that time we scheduled over at the, over there they'd bathe her and help her with that over there. But when she, she came back to the apartment, I'm the one who had to do it. For a while there I was helping her up and helping her down, making sure she was comfortable I was the one helping her making sure she was comfortable in bed making sure she got up at night to go to the bathroom, helping her change her diapers, all that sort of thing but/

X says when his wife was on the health care side of the facility the staff took care of grooming tasks but when she returned to the apartment that was his responsibility	When his wife wasn't at the care center he had the responsibility of total care.	He felt completely responsible for his wife's comfort and care, which is very physically demanding.	He became responsible for her physical comfort, hygiene and well-being.
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Well I didn't like it I'd made I made a commitment when I got married, you know the better or worse thing, I made that commitment I was going to stick with it as long as I could, unless I was going crazy myself, well it was a real drain on my energy, yet I felt she, we'd been together so long I owed that to her, and it was probably one of the best ways I could show love for her even though she swore up and down I was, that I'd lost my love for her, she was—that I was—that I was just trying to push her aside well, nothing was further from the truth./

X states although he didn't like having to do the personal care he had made a marital commitment, which he would honor as long as he was able. He felt this would demonstrate his love for her even though his wife insisted he no longer loved her and believed he wanted to get rid of her.	Total care is very hard work but X feels he owes this to his wife because of all their time together as well as the commitment he made when they married. He feels it demonstrates his love even though his wife accuses him of abandoning her.	He struggled with his sense of commitment to their long relationship and the difficulty of all day care. It was a way of demonstrating love even though she did not recognize it as such.
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I guess when you're in a certain state of mind things look different to you, obviously, and they did to her, and it kind of hurt because I was trying my best but I don't think she'd recognize it, it got to the point she couldn't recognize,

X feels his wife is unable to recognize his efforts to care for her and the implication of love, despite his best efforts.	It was painful to try so hard and not have the effort recognized.	Her response did not validate his effort he had to call on earlier memories to keep the situation in context.
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At least during the last few months she had been in and out of the hospital, especially U, she had been at U. psych unit probably 3 or 4 times and they kept telling me this is not, what this is more of a psychological problem than a psychiatric problem but uh they were giving her, they were giving her some meds that were working pretty good but being over there all the time, I bet she stayed more in the hospital or the care side more that the apartment here. I bet 2 months is actually how much she spent in the apartment in total so, so it ended up she was over there, she was getting pneumonia, and of course they couldn't control it over there so they sent her back to the hospital in one of the medical surgical wards instead of the psychiatric unit, well supposedly she got over the pneumonia but they finally diagnosed what

a lot of people had suspected for a long time and that was she was having little strokes, minor strokes, and it would affect her speech it would affect her thinking, her movement /

X reports his wife had multiple hospitalizations towards the end of her life both psychiatric and medical. During this period she was diagnosed with TIAs that impacted her thinking, speech and movement.	During the last few months of her life X got some relief when his wife was in the hospital, mostly psychiatric, then with pneumonia. During this period she was diagnosed with TIAs, which explained the problems with speech and movement.	It was a relief when his wife was hospitalized which happened frequently over the last months.
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And I guess the thing that made me angry was that one of her last lucid moments before she did pass I asked her about this, "Have you been having strokes all this time?" And she said "yes." I said, "Why didn't you tell me?" This was one of her problems she never really told me how she felt, to this day I don't know how she felt at the time she was in the hospital I just assumed from what the doctors told me and what I observed well that's probably what took her were these strokes, she got to where she couldn't talk or if she could talk got to making rough sounds where she was voicing sounds./

X was angry that his wife had been having strokes and did not tell him, that she rarely told him how she felt and it was probably the strokes that caused her death. This still bothers him.	X was angry that his wife had not shared how she was feeling with him, or told him about these strokes that probably caused her death.	He was angry when his wife revealed that she had been withholding information. He feels this information might have made a difference.	He persisted in expecting rational responses, when he didn't get them he was angry.
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Her memory had been, it was slipping it was probably, there were certain things, they were treating her over here as pre-, old, pre-Alzheimer's, dementia. She went, she had, her doctor sent her to Scottsdale for Mayo—I think that was 2008 she went to Scottsdale. Well they did a work up on her and they didn't find too much physically. But one of the things they suspected, they could never pin it down, she was having mini strokes even at that time. They wanted to do further work on her but we couldn't afford to live in Phoenix or Scottsdale at that time./

X says his wife had been diagnosed with TIAs in 2008 and also was told she had early Alzheimer's disease but further workup at the Mayo clinic would have been costly requiring them to live where they could not afford.	4 years before X had taken his wife to the Mayo clinic where she had been diagnosed with TIA's and told she had early dementia. They declined further workup due to lack of propinquity or money.	The idea of dementia, Alzheimer's is an afterthought, he recalls 5 years earlier they had been told this was the situation, not clear what the implications were.
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She had been a registered nurse at one time. In fact, she retired 2-0-0-6. She retired from nursing. If she was going to be a good nurse she would have to go back for more credits, to get a bachelor of science, but she didn't want to do that. She wanted to take retirement and enjoy that as long as she could./

X's wife had been a registered nurse, instead of maintaining her license they retired early.	X recalls his wife's retirement from nursing 2 years before the Mayo clinic visit.	Recalls his wife had retired early to enjoy life while she had the chance.
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Married for 30 years. All down through the years we were together I loved her very much and uh I may break out in tears, I loved her very much and it hurt to see all this happening and sometimes I was a victim of her aggression and of course that was something they tried to correct as best they could but uh she'd be very aggressive for a while then she, she would calm down, she would be like what you'd call a normal person, whatever that is and I don't know if there's anything such thing as a normal person we all have our quirks but, I worked with it, lived with it, didn't enjoy it, had a rough time it was rough her problems made it very hard to work, to plan vacations we had at least a couple vacations planned 2009–2010 and we had to cancel both of them. She was just not ready to travel anymore and uh Doctor at that time and our pastor said give it a little time and it may blow over and you guys can still be able to do what you want to do, but it never blew over, it just got worse./

X reports intense love and emotion for his wife of 30 years through times of her intense aggression and periods of normalcy, though this impeded working and taking vacations. Despite hoping for improvement, things got worse.	X expressed his love for his wife over their 30-year marriage, despite her difficulties, that he dealt with her changes as it affected his work life and their personal relationship and their plans for the future.	Reminiscence of good times helps ground the experience to a positive perspective despite the overwhelming grief and hardship.
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I don't know, my feelings were, let me stack up the words: ah frustration, despair, um lack of hope, maybe just because it seemed like, that things were just not going um well helping her out, most basically were things I didn't feel I should be doing, didn't want to be doing but since I was the principal care provider it was my, basically my job./

X expresses frustration, despair and hopelessness regarding his experience because things were not going well and he didn't think he should be doing what he was doing but as primary care provider there was no one else.	X was frustrated and despairing, his help did not seem to help his wife and he was the main care provider.	Felt hopeless and helpless while experiencing the continued decline that forced him into the caregiver role.
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Going to the bathroom, getting dressed and undressed, uh taking her shopping, things like that, some of those weren't too hard. Taking her shopping wasn't that hard. I could always take her on that thing (walker) or her wheelchair take her places that way, but the basics around here, like I say dressing undressing bathroom, showers, they were hardest because she was hard, she was hard to lift, she probably weighed 185–189 pounds./

X assisted with toileting, bathing, dressing, and shopping which was mostly difficult due to his wife's weight and his difficulty lifting her.	This was total care, physically demanding for an older man, non-stop, additionally difficult because of her weight and his weakness.	
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Somewhere in there, she was sedentary for a number of months so she wasn't losing weight, and her eating habits varied. While she was here, she would usually eat what they put in front of her there were times when she wouldn't touch it, times when she didn't want to go down to the dining room anyhow I imagine it was times when she didn't feel good physically. Which was probably the reason, the pneumonia bit made it hard for her, trouble breathing they even put her on oxygen. When they thought the pneumonia was getting better they took her off of it and when she showed signs of improvement they took her off of it./

X reports that getting his wife to eat was difficult: sometimes eating what was put in front of her and sometimes, he thinks particularly when she wasn't feeling well physically, not eating at all.	She had been sedentary so that contributed to the weight gain, X talks about her eating habits, sometimes very finicky.	Her needs were not predictable, refusals of different kinds of care was frustrating. She was not docile.
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She didn't like living over there, because as I said they put her in the unit, the mental ward—the dementia, when she'd gone to, when she had been to Mayo in Scottsdale they said they detected that she had a frontal lobe dementia problem, so I don't know how extensive that dementia problem was and I was told it was one of the first stages, it didn't seem to bother her though she forgot things once in a while She wasn't one to go out and get lost to wander. She was; in fact, she didn't go out that much anyway unless it was with me./

X states that his wife did not like living on the healthcare side of the facility because they would transfer her to psychiatric care. He recalls his wife had been diagnosed with fronto-temporal dementia, but he was unaware of signs or symptoms of this although he recalls she forgot things from time to time, She did not wander. She did not venture out much at all, and not without him.	X says his wife didn't like being on the care center side of the facility because they were quick to send her to the psychiatric unit. He reflects upon the frontal lobe dementia diagnosis, looking for what that might have meant in terms of her behaviors and actions, specifically memory and wandering.	In retrospect he is trying to make sense of his wife's situation and his care giving experience. Did not give much credence to the dementia diagnosis.
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That was one of the places we, she did go We lived in a mobile home she would go walk over there to visit the manager and his wife and they'd talk about things spiritual and material and she kind of liked that talking more of what she was after I think.

I think she was after help, but she didn't really know where to look for it, she wanted somebody that would talk to her and reassure her that things were all right. Those people weren't the ones who could do it, should do it. They were the ones she normally went to. Or she'd call she would make telephone calls to friends in the area that she could talk to She

didn't have a lot of visitors, our church pastor came over a bit, and some of our better known friends would drop by and see us but she wasn't a joiner at that time either. She wasn't a member of any women's organizations, anything like that./

X says his wife sought reassurance and help via conversations and phone calls with random people from their surroundings that X didn't feel were the most appropriate for that purpose,	He recalls a pattern his wife had of seeking out people to talk to about spiritual and material matters.	His wife sought out non-conventional connections for support. He was aware of her feelings of emptiness.
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When I first met her she was very active in the church and it kind of gradually slipped away from her. She had been active in women's bible study and she was active in stuff like quilting and doing things that helped children doing things like that. Later on in our marriage she started dropping all that things like that for one reason or another. Or maybe she felt she was too involved or the stimulus wasn't there./

Over the course of their marriage and as she got worse, she dropped favorite activities.	Over time his wife had lost interest in her usual activities and hobbies.	
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Um in the last year, well she wanted to stay at the bible study if she could, she got interested in knitting and crocheting, things like that, she was doing that up here almost 'til the time she passed, When she passed apparently, I can't say she was in pain or anything like that because she couldn't talk and she couldn't express herself so I can't say how she really felt. I think that there was one thing that she had they never cleared up and that was a bladder infection that would hurt her. That would be painful every once in a while, she acknowledged that with ouches and stuff like that. She was trying to knit caps woolen caps for different people she had in mind, but she never finished any of that. The only thing she finished was stuff she did years and years ago when we first met./

She picked up and dropped activities in the last year until she died. She couldn't talk so I don't know if she was in pain, but she made pain noises from a bladder infection that was never cleared up.	In the last year she had few interests, would start but not finish projects. X doesn't know how she was feeling when she died, but recalls she had a urinary tract infection and seemed to feel discomfort from that.	The last year of her life was starts and stops and inability to share her experience with him.
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I feel I did the best that I could, I kept that commitment, I made the commitment, did the best that I could. I still I look back, I talked to the pastor about this, the fact that when she was sicker, did I miss something that would have helped her out more than I did, in the back of my mind was there more I could I have done? Looking back I don't know what that could have been I guess he did decide the rest because he took it out of my hands. And like I said, my pastor and C. over there said you did what you could, the most that you could. God decided the rest and I guess that's true; he did decide the rest. It was out of my hands, /

X feels he did the best that he could, he stuck with his wife and the rest was in God's hands, but still in retrospect he has doubts that there might have been things he overlooked that would have made a difference.	X repeats that he did the best he could, he kept his commitment but can't help wondering if there was something he missed or a way he could have done better. It was in God's hands.	Despite feeling he did the best he could he has doubts.
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It was unique I was trying to keep J., I was trying to keep her at the care center and qualify for Medicaid, I got shot down twice because we had too much money, that's a joke so we got through that and of course I'm surprised they always had a bed ready because sometimes those people are full and they have a candidate waiting 'til they have a bed over here for her especially since she used to live in the apartments and then they move her over there but ah.../

It was difficult to get Medicare but they did with the assistance of staff at the facility. X expressed surprise that the facility had open beds when they needed one.	X was trying to get financial resources to help with his wife's care; he was appreciative that the care center was always able to accommodate them.	The care facility assisted him with Medicaid application as well as in patient care when she needed it.	He was trying to access resources for long term care when she died.
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There were physical barriers, I couldn't lift her so I had to call if I had needed help to lift her or move her I had to call someone on duty like security or a nurse, and of course when I did that they'd bring the whole crew over here to check her out when quite often that wasn't what I needed, I needed to get her off the floor she fell a number of times because of not being able to move her legs, /

Lifting was difficult and at times X had to call for help, a whole crew showed up more than he needed. She fell several times.	His wife fell several times and he couldn't help her up himself. The help that responded was more than needed.	Physically transferring his wife was a major problem for him.	His wife's weight and his weakness exacerbated the difficulties; the facility's resources were inadequate.
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From here on down it was just, everybody tried to figure it out no connection between here and there seems like the wiring was faulty or something like that because she could move her legs, at first she could move her legs, and she could walk at least with a walker and then gradually declined to the point where she couldn't do anything and it was a mystery to me I wondered, I tried to keep her out of a wheelchair, because I knew once she got into a wheelchair we probably couldn't get her back out that's exactly what happened eventually but the part about not being able to walk that still mystifies me but I would suspect it probably was the stroke that did that just cut the wires that controlled the panel you might say. And I was willing to work with that. In fact, I did for quite a while. She did use her arms to push up. What with that and me helping her, she holding onto things, she could stand up, but she always needed some kind of support. She couldn't stand freely, but it would be enough with all that to get her from one seat to another seat, or from a seat to the bed, or the toilet, or to get her up and get her dressed./

<p>X states that from the waist down his wife had difficulty with mobility, which is a mystery to him. He thinks it might be related to strokes. She declined to the point she was in a wheelchair, which he had been trying to prevent. She was only able to help with her arms, which made care giving difficult.</p>	<p>X did not understand his wife's rapid decline; he thinks maybe it was related to strokes. He knew once she needed a wheelchair she probably would remain in one. Lifting her in and out of the wheelchair was a big concern because she could only help with her arms.</p>	<p>Mind-body connections were disrupted. His wife becoming wheelchair bound was a significant event symbolic of decline of no return.</p>
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We had several girls, we had home health come in here for a while to help her out during those crucial times but that was a sad thing too. Once, J had been a nurse and she thought she knew it all, she thought she knew nursing better than anyone else did she just aggravated everyone they got to the point they didn't want to do anything for her or with her because she was so critical of everything they did, and I know why being a nurse being a registered nurse at one time and had her ways of doing things and woe be the person who tried to tell her this is better than this so the hard part there was we lost all our help after a while she ran them off, that I didn't like that either I was getting tired of doing all the lifting and waiting and serving stuff like that and here were other people to help me out with it and they weren't going to stand around and take the abuse they were getting she was giving them so I don't know they finally just quit./

<p>X reports they did get helpers but his wife behaviors and global criticisms alienated them so they wouldn't come back to be abused which left him doing the heavy lifting and serving.</p>	<p>The people available for in home help were inadequate to deal with his wife's emotional behavior; they felt abused which left him having no help with her total care.</p>	<p>His in home help was inadequate to deal with the situation.</p>	<p>Disinhibition/ behavioral problems alienated potential help leaving him with the burden of care, and wife's abuse.</p>
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I'm still as you can see I'm probably still turning it over in my mind as to what I could have done what I did do. It's not the fact is gone now that settles that problem I don't have to worry about it, its back in my mind I run through it and I wonder could I have done this better. Could I have done that better, what did I miss and that's the way it has left me but I am getting on with my own life I'm able to uh I'm not able to solve any of it but I am able to dismiss it put it back where it belongs now because she's gone now and I've taken a number of steps to keep myself going and everything like that. I miss her but I know she's not coming back so gotta keep moving. I don't know if all this has helped you or not, but I um yeah I still have questions about how the way things went, you know how things might have been they could have been different and we might have done things better, I'm probably wasting my time there because there's no way I'm going to make things better for her. She's gone, so/

Mr. X reports continued ruminations about if and what he might have done better but he feels he needs to dismiss those thoughts and focus on his own life now she has died.	Even after his wife's death he continues to wonder if he could have done things better, he knows this is wasting his time and won't change things.	Even months after his wife's death he continues trying to make sense of the situation his actions and choices.
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I think I've talked about this a little bit before She had been over at the care center for quite a while they were doing the best that they could to keep her happy and to keep her in good spirits because they were truly trying to help her motivate her to get to get her out and do things and it seems like she just fought them all the way, even there she got to the point where certain people didn't want to help her, or wait on her because she would say things to make them angry she would get angry I don't, as I say she was a nurse and she had her own way, but I don't think that was entirely the reason, I think there was frustration on her part and the fact that she, I'm sure she was scared out of her mind at the way things were going. She couldn't see things getting any better and I think that it really truly bothered her, and there were a number of things, she had the help of a pastor resident pastor here C and her own church pastor and they came to see her quite often, here and in the hospital too. I don't think she had the reassurance apparently she didn't have the reassurance that she was looking for. And as I say she fought being over there she wanted to be over here in the apartments and she had chances to do that but that didn't work very well either so I imagine there was a lot of frustration on her part and as I say fear—scared of how life was going, what was going to happen to her and she didn't like going to the hospital really she wanted to stay out of there as many times, as long as she could till the last days she said, “well take me back to the hospital things aren't going right around here send me back there.” I said, “What for? Just because you want to go?” She said, “Well, I'm out of control and things aren't going the way they should be going.”/

X recalls behavior of his wife that alienated staff, and states that he thinks her anger and behaviors had to do with being scared of her declining condition and awareness especially having been a registered nurse that she was not going to improve. Pastoral care did not give her the reassurance she was looking for.	In retrospect X feels a large part of his wife's behavior problems were because having been an RN, she was aware of her situation and was scared, angry and frustrated and wasn't able to control any of her circumstance.	His wife was aware of her situation, and her decline; she was scared angry and frustrated by the situation, which led to her behaviors.
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I think actually she went to the hospital, they put her in as I said behavioral health, behavioral health sent her to the med surg ward because of pneumonia. They eventually said well things are going such they eventually said hospice is the only answer for J, and I guess it was. It wasn't. I think she just gave up. It wasn't even a week and she's gone, a week after she got up there. But that's the way a lot, a number of other people feel she just gave up, didn't want to live anymore I guess, but because of the fact she couldn't communicate that well./

X says his wife's last admission to the hospital was to the behavioral health unit but they transferred her to a med surg unit because of pneumonia and made a hospice referral which he is ambivalent about but does agree with a number of acquaintances/ friends who feel she just gave up and did not want to live anymore because she could not communicate.	His wife declined to the point she couldn't communicate which made her give up.	His wife did not want to live the way she was and gave up.
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That kind of hurt too. I was doing the best I could to keep her alive and well and staying part of the family in fact the day she passed I got a call from the nurse that morning and well Johanna isn't doing that well heavy breathing pulse is up blood pressures up and temperatures up but it was in the morning she said I think I can keep it under control. But you might think about coming down. Well. When she said that I got dressed and I did a few things even went to the mortuary down here talked about final arrangements so I got home about lunchtime. They called the same nurse I got a call said Mr. S you better get down here I don't think she has much time so I got down there Well I got there but she had already been gone 10 minutes or so but uh yeah I think she just gave up, didn't have anything to live for anymore at least the way she looked at it probably, I don't know how do you communicate with a person like that, is there any way you just talk to them you don't know if they don't hear you or not if they can't blink their eyes or anything like that just you assume that you're talking to someone and maybe she hears you or not, but you have to live with that./

X says his wife's resignation, giving up hurt him because he was working hard to keep her alive and well.	He was trying to keep his wife alive and interested but she felt she had nothing to live for and he was unable to communicate with her.	He feels he was unable to keep her interested in living—this was a failure.
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But as far as my own working with her, yes I had my own frustration I had a lot of times when I was, wished someone else was there to do things for me but as I said before I made the commitment, and I figured I ought to stick with it. And I did somehow. It wasn't easy because all the reports I got pointed to her going downhill, not getting any better, o for a while they said well, now that she's here in the care center well run her through physical therapy and she'll come out a lot better, but it didn't, they didn't, they couldn't even give her all the stuff they even promised, the help they keep telling you when you're over there, this is not a hospital this is just a care center, if she needs all this extra stuff she needs to go back to the hospital but at the hospital they got tired of her I got tired of driving down there all the time./

X reports during the time he cared for his wife, he often wished there was someone else who could do the work but he stuck by his commitment. He says he kept hoping for improvement but was frustrated by the continued decline and no improvement at either the care center or hospital.	Care giving was tedious and frustrating and he wished he had help but he had made the commitment and stuck with it despite a growing lack of hope as his wife declined.	Added to his frustration with the physical care was the poor prognosis and downward trajectory.
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She was in there a week each time, 8 days something like that, and I got tired of driving down there although I didn't go down there every day because I didn't feel like it was doing any good./

X reports with his wife's multiple hospitalizations he didn't visit the hospital every day because he didn't feel it did any good.	He felt ineffective.	
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But I'd go down and see her occasionally, when there was a visitor. Sister, my brother Ron, my sister Marilyn, all came one time. It was a good thing they did, because I was needing some mental support at the time. They came and they visited J. It was great. They had a great time. She had a great time with them and I had a great time with them, but support from the family was pretty hard to come by because nobody lives here. Nobody lives in Albuquerque or New Mexico, even. They all come from California and it was it was a challenge to get the airfare and make arrangements and all to get them out at the same time, so I don't know./

X said he did visit occasionally and recalls a time when his brother and sister came from California and they all visited together and had a great time. X felt he was lacking family support, which has been difficult due to the distance and expense of their travel.	When he had mental support/ reinforcements from family or friends they all enjoyed the visit.	None of his efforts were making a difference, family and social visits boosted her spirits.
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I don't know if I've answered your questions or given you any material, but you can certainly listen to it and pick out what you feel is useful.

X concludes, wondering if he has helped me.		
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Interview 1 Structure

There was a 10-year decline resulting from the psychological disorder. A specific event 20 years ago identified a background psychological problem, as well as a history of unsatisfactory interactions with both medical and behavioral professionals. The background problem was stable for years. His wife's thinking and behavior changed. He could not relate to her rationally. He looked for a medical explanation. He felt helpless to deal with the situation but didn't feel like the medical/ psychological help was doing any good. A temporary delicate balance was reached. The decline in his wife's health resulted in major life changes including moving to a retirement / independent living home. His wife's thinking and behavior was irrational, he could not get through to her. His wife feared his abandonment of her. There were multiple hospitalizations for behavioral problems. He tried to fill in by assuming her responsibilities but his efforts didn't meet her irrational expectations. No medical help could stop the continued decline. The brain-body disconnect got worse and she became more dependent for ADLs. He expected improvement. His wife was aware and distressed about her decline. He became responsible for her physical comfort, hygiene and well-being. He struggled with his sense of commitment to their long relationship and the difficulty of all day care. It was a way of demonstrating love even though she did not recognize it as such. Her response did not validate his effort he had to call on earlier memories to keep the situation in context. It was a relief when his wife was hospitalized which happened frequently over the last months. He persisted in expecting rational responses, when he didn't get them he was angry. The idea of dementia, Alzheimer's is an afterthought, he recalls 5 years earlier they had been told this was the situation, not clear what the implications were. Recalls his wife had retired early to enjoy life while she had the chance. Reminiscence of good times helps ground the experience to a positive perspective despite the overwhelming grief and hardship. Felt hopeless and helpless while experiencing the continued decline that forced him into the caregiver role. This was total care, physically demanding for an older man, non-stop, additionally difficult because of her weight and his weakness. Her needs were not predictable, refusals of different kinds of care was frustrating. She was not docile. In retrospect he is trying to make sense of his wife's situation and his care giving experience. Did not give much credence to the dementia diagnosis. His wife sought out non-conventional connections for support. He was aware of her feelings of emptiness. Over time his wife had lost interest in her usual activities and hobbies. The last year of her life was starts and stops and inability to share her experience with him. Despite feeling he did the best he could he has doubts. He was trying to access resources for long term care when she died. His wife's weight and his weakness exacerbated the difficulties; the facility's resources were inadequate. Mind-body connections were disrupted. His wife becoming wheelchair bound was a significant event symbolic of decline of no return. Disinhibition/ behavioral problems alienated potential help leaving him with the burden of care, and wife's abuse. Even months after his wife's death he continues trying to make sense of the situation his actions and choices. His wife was aware of her situation, and her decline; she was scared, angry, and frustrated by the situation, which led to her behaviors. His wife did not want to live the way she was and gave up. He feels he was unable to keep her interested in living this was a failure. Added to his frustration with the

physical care was the poor prognosis and downward trajectory. He felt ineffective. None of his efforts were making a difference, family and social visits boosted her spirits.

His wife died 8 months ago from a combination of medical problems. Even now he wonders if he could have done better, yet he did the best he could. He can recall a specific event that seemed to be a catalyst to all that followed. For the last ten years he has been caring for his wife as a result of psychological, physical, emotional and cognitive problems entailing frequent, mostly unsatisfactory interactions with medical and psychiatric professionals. This process required many readjustments and only tentative, ephemeral balances.

A primary feature of this time was his wife's irrationality. He recognized it as such but continued to try and reason with her, a situation that led to frustration and anger on both their parts. Their relationship was volatile at times abusive. On occasion police were called, often leading to ER visits and psychiatric hospitalizations. He relied on medical and psychiatric professionals who did not provide practical help—it did not help with day-to-day getting along. The gradual decline in his wife's general health as well as psychiatric and cognitive led to decisions about moving from their rural location closer to medical care and into a senior living apartment connected to a long term care facility. As she declined and did less of what she used to do, he found himself doing more, which seemed to aggravate his wife because it pointed out her declining ability.

He could not communicate with his wife, she seemed irrational and angry and at the same time said things indicating she was afraid he would leave her. He could not understand what she was going through. He felt ineffective. None of his efforts were making a difference. There were multiple hospitalizations for behavioral problems and during this time her physical condition weakened. No medical help could stop the continued decline. His wife needed his help for mobility, hygiene and nutrition. She needed to be lifted in and out of a wheelchair and lifted and turned when changed and bathed. This became total care, physically demanding for an older man. This was nonstop, round the clock, additionally difficult because of her weight and his weakness. He often had to call for help to transfer her in and out of the wheelchair or to help him lift her off the floor if she fell. Gradually he became in charge of their lives together, still he held onto hope and expected improvement. When his hope for improvement waned he would feel desolate and loss for their lives together and any interesting future. He feels he was unable to keep her interested in living this was a failure.

She had made a decision to retire early in order to enjoy the rest of her life. But over time she lost interest in her previous activities as well as her surroundings. She would call out or refuse care unpredictably as expressions of frustration and anger. She reached out to random people as well as spiritual counselors grasping for traction and connection with anyone other than her husband. She was aware and distressed about her decline; she understood the implications as she became dependent on her husband for her physical comfort, hygiene and well-being. Becoming wheelchair bound was a significant event symbolic of a decline of no return. She did not want to live the way she was and gave up.

He struggled with his sense of commitment to their long relationship and the difficulty of all day care. He thought of it as a way of demonstrating love even though he did not think she recognized it as such. He wanted her to act more grateful because her responses did not validate his efforts. He would reminisce; call on earlier memories to keep the situation in context but had there seemed to be a paucity of good memories. His only relief was when his wife was hospitalized which happened frequently over the last months. He felt hopeless and helpless while experiencing her continued decline that forced him into the caregiver role.

Interview 2

The first time I ever noticed that P. had a problem was back in 2007. We were in Switzerland. I noticed she told some people we were having lunch with she told them the same story twice. And I thought, well that was real unusual for her to do that. So then just, oh a little bit gradually, noticed more and more her trouble with her memory./

Mr. Y states he first recognized his wife had a problem was when they were traveling in Switzerland in 2007 and she repeated the same story to the same people twice. After that he noticed a gradual worsening of her memory.	A specific event brought about Y's realization that his wife had a problem.	Now he sees life as before and after a specific event.
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So we mentioned it to her primary care physician who gave her some medication called Namenda, it was a low dosage, it didn't seem to have much effect this was probably I guess a year ago./

Mr. Y mentioned the event and observations to the primary care provider who prescribed Namenda.	They informed her primary care provider and she was started on medication.	Medical intervention began with medication.
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And so things were declining so I wrote to her doctor and asked her to recommend a neurologist which she did and went to see the neurologist who said well let's cut to the chase and got a neuropsychologist to do a study, went to see Dr. ___ who gave her some tests and said her memory, her short term memory was poor and she said that can't get a definitive diagnosis of Alzheimer's unless on autopsy and we weren't ready for that (they both laugh) So she said it sure looked like it was leaning towards Alzheimer's so we went back to the neurologist and he increased her Namenda and she gets along fine with that and ah has it made a difference? I don't know I can't really tell. Ah, she gets along pretty well. At the time we met with the neurologist, that was November, he suggested that she quit driving, which she has./

Mr. Y contacted their physician as he was noticing a continued decline and requested a neurology referral. Neurology referred to neuropsychology where a battery of tests were conducted concluding probable Alzheimer's. This was conveyed to their PCP who increased the medication. Y doesn't think it has made a difference.	Y requested a referral and his wife was evaluated by neuropsychologist, which led to a presumptive diagnosis of Alzheimer's. Her medication was increased, although he doesn't notice a difference. His wife quit driving at the neuropsychologist's recommendation.	Decline led to more medical intervention and a clearer diagnosis.
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. . .Went to see Dr. ___ who gave her some tests and said her memory, her short term memory was poor and she said that can't get a definitive diagnosis of Alzheimer's unless on autopsy and we weren't ready for that (they both laugh)

Finding humor in their shared experience.	They are able to find humor in their shared experience.	
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And, um, so I've taken over a lot of the responsibilities, grocery shopping, and some meal preparation. That's kind of where we are today. /

Mrs. Y's continued decline required him to take on roles she had previously assumed.	Husband has taken on more daily responsibilities as wife becomes unable to continue them.	
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Ah she tried, the neurologist prescribed some medication, Exelon, and Aricept, and those don't agree with her. They bother her stomach, so ah she can't take those, I know. Ideally try different combinations what we strive for. Namenda seems to be working, so that's about it./

Mr. Y relates that the neurologist prescribed some other medication combinations that he understands is the ideal treatment, but some his wife could not tolerate but he thinks the Namenda is working (represents ambivalence towards effectiveness)	They tried different medications and stuck with the one she tolerates.	Ambivalence about effectiveness of treatment.
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Day-to-day life—um, well, we still each get our own breakfast and lunch, and in the evening we have a meal. I'll fix it or we'll go out or I'll bring something in and, uh, I don't know. We're retired, so we take life easily./

Mr. Y reports that their day-to-day eating habits haven't changed yet, notes they are retired so take things easy.	Awareness that they are at the beginning of a process of change.	They know that the situation will get worse.
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She used to read a lot she doesn't do that much anymore reads the paper in the morning and uh uses the computer some; special computer game she likes or watches basketball on television but after the game is over she doesn't even know who won./

His wife's intellectual habits have changed; she can watch a ballgame and immediately forget who won.	Wife is less engaged in activities, more superficial involvement.	Wife's identity/ personality is changing, he doesn't know what to expect as time passes.
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I don't like it, but I realize the disease is progressing and that there isn't a whole lot we can do./

Mr. Y does not like this state of affairs, but feels he can't change anything.	Y feels that decline is inevitable.	Sense of powerlessness with the understanding of inevitable decline.
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[Wife] He's always been a good helper./

Mrs. Y acknowledges his help.	Mrs. Y is aware her husband is making up for her deficits.	
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As far as housekeeping, we have a company come in every 2 weeks. Takes a little burden off and I do all the financial, um, business type./

Mr. Y states they have outside help for housekeeping and he has taken over the role of financial management.	They have hired housekeeping help; he has become the household financial manager.	There have been a role changes.
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[Wife] Well you've always done that

Mrs. Y reports he has always taken care of finances.	Wife diminishes the change attempts to remain optimistic.	Wife tries to maintain feelings of normalcy by diminishing changes.
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Well, not always.

Mr. Y disagrees.		
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[Wife] He's been a banker./

Mrs. Y supports her statement by recalling her husband was a banker.		
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Um, I don't harbor any ill feeling. It is what it is. We have to deal with it. Well, I wish she could still drive. Well you know she sleeps a lot more now. I don't know if it's the disease or medication manifestation, but ah, I, I don't, you know, look at anything as being a negative—sure I wish she didn't have this./

Mr. Y repeats that he doesn't have ill feelings or look at the situation negatively but wishes she did not <i>have</i> this. His wife is unable to drive; she sleeps more—related to the disease or medication side effects.	He is not blaming anyone he knows they have to manage the situation. His wife no longer drives, making her more dependent on him.	Changes in his wife are significant, distressing and he isn't sure if it is medication or disease. She is unable to drive herself literally and figuratively.
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She's asked me four or five times today she's asked me when we were leaving to come here and you know it gets a little old being asked the same question over and over but it's not a problem. Ah, she used to like to have people over to dinner, but I don't think she cares about that. She's a quilter and does beautiful work quilting. She meets with a group at church

twice a month and I encourage that for socialization. She sang in the choir until Christmas time; decided it was too much stress. I can't think of anything./

<p>Mr. Y reports that its tiring being asked the same thing repeatedly but insists it is not a problem. His wife used to like socializing, which she doesn't anymore except for attending a quilting group. Y says his wife stopped attending choir because it was stressful.</p>	<p>His wife repeats the same question over and over which gets wearing yet he maintains it is not a problem. She socializes less compared to having enjoyed having dinners. She continues to quilt and until recently sang in the choir. Compares and contrasts before and after.</p>	<p>Communication is repetitive and not retained. She is engaged less in social activity but retains some interests.</p>	<p>Having to repeat answers over and over is aggravating for him, particularly since he knows she has no control over it making him feel angry, sad and guilty.</p>
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Maybe this has gone on longer than I realize, out of the ordinary./

<p>Mr. Y considers the possibility that symptoms have been present longer than he realized.</p>	<p>Recalling details of the situation leads to the consideration that changes were happening before the initial incident.</p>	<p>When he talks about it his perspective changes from the day to day to the entire experience, what it means and how long it has been going on.</p>
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We pretty well shop together./

<p>Mr. Y says he and his wife shop together.</p>		
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[Wife] I always made lists before we went anyway./

<p>Mrs. Y reports that they've always made lists before shopping.</p>		
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Well the grocery shopping that was another... she used to make a list for the grocery store and it was kind of mapped out according to where things were in the store, like you start here go around there and wind up at the cash register. One time we went and it was just like she didn't know where anything was. So I've been doing most of the grocery shopping here lately, she goes sometimes and she stays, I don't have to worry about her wandering off, anything like that you know things are definitely different but it's hard to really state what they are just realize that's part of the disease/

<p>This reminds Mr. Y of differences grocery shopping. Previously they had a list according to location and now Mrs. Y doesn't recall the location of items. Mrs. Y accompanies him shopping sometimes. He does not worry about her wandering off. He reflects that there are many differences now but it is hard to state exactly what.</p>	<p>Mr. Y notes more differences, that when shopping—she used to plan in orderly succession and now it is more random.</p>	<p>Previously she was organized with spatial and sequential awareness as demonstrated by a shopping routine, which has now become random.</p>	<p>The “disease” has taken on a life of its own.</p>
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We have a son in Atlanta and our daughter lives in Fort Worth, and ah we're going there next Tuesday for Easter. We like to travel. After that we're going to Europe do a cruise down the Rhine River in May and June will be our 50th wedding anniversary so we're taking the kids and grandkids on a cruise up to Alaska. And then at the end of August, we're going to Sarasota Florida to visit some friends./

<p>Mr. Y reports that in the next 5 months they will be traveling to visit their children, cruising down the Rhine, celebrating their 50th wedding anniversary with children and grandchildren with a cruise to Alaska and visiting friends in Sarasota.</p>	<p>They will be traveling to see friends and family while they can still enjoy it.</p>	<p>They want to maintain social activities with family and friends. While they can still enjoy it.</p>	<p>He tries to maintain the routine ordinary part of their lives.</p>
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Her sister lives in Corrales and we see them frequently, if I ever needed a short term substitute care giver her sister.../

<p>Mr. Y reports his wife's sister lives close and is available to help with care,</p>	<p>They have family close by who can help with care if they need it.</p>	<p>He is assembling a support network.</p>	<p>His wife is unable to be left alone, she requires constant vigilance.</p>
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(Wife) And well some of the friends we're going with—he has Alzheimer's, not my brother-in-law/

<p>Mr. Y's wife adds that one of the friends traveling with them has been diagnosed with Alzheimer's as well.</p>	<p>One of the friends they will be traveling with has Alzheimer's. They have some comfort and support here.</p>	<p>In their social circle there are others in similar circumstances.</p>	<p>Wife tries to minimize and normalize the situation</p>
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Yup. In our church we're starting what we call a memory café and, uh, we have five or six people with Alzheimer's or some sort of dementia. We just started, had our first. I guess they're doing this in Santa Fe, and we'll probably open it up to the public./

Mr. Y reports their church is beginning a program for parishioners with dementia that they will probably open up to the community.	Their church provides support and help.	He is assisting in the development of social support structures in anticipation of future needs.
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We just stake out an hour, hour and a half in the afternoon, Saturday afternoon, and we have light refreshment and usually some computer clips of something from the old days, triggers, something to talk about might be animals, could be what a 1940s gas station looked like stuff like this um I think Lynn plans to have some speakers, we'll see how it goes./

Mr. Y says this involves 1–1 ½ hours with refreshments and memory triggers to stimulate conversation.	The Church program will support the folks with dementia as well as their partners.	He is formalizing support structures by assisting in a church program for people with dementia.
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I'm thankful it didn't happen sooner in our lives, but ah, I always thought if something, you know, dreadful would happen, it would be me and she would end up being the caregiver; but I have no regrets./

Mr. Y reports he is thankful this happened late in their lives; he thought if something happened with their health, it would have been his wife caring for him. He reports no regrets.	He had imagined that if this came into their lives it would be his wife caring for him.	He had not foreseen himself as care giver, thought it would be his wife caring for him.
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I'm in charge of her medications we have those for morning and evening I put all the medications—remind her to take them and take care of all the medical appointments./

Mr. Y reports specific care duties include administering medications and scheduling, keeping appointments.	He manages and schedules both their lives.	
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[Wife] He did a lot of that before just because he liked to do it.

[Husband] It wasn't always. She was the organizer./

Mrs. Y reports this is how it was always. Mr. Y refutes this.	Mrs. Y minimizes role changes.	
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I think one thing I've noticed, in social situations she's more guarded, she knows that she might slip, up ask the same question twice, so she kind of protects herself in that regard. Well I don't feel that I've needed to protect her, but um we get along reasonably well/

Mr. Y has noticed his wife is guarded in social situations, afraid she will slip; he doesn't feel he has needed to protect her and states that they get along.	His wife's social behavior has changed; she is less spontaneous.	They are self-conscious and protective of possible slip-ups—they live with the stigma of dementia.
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(Wife) I wish I didn't have it but I do so I have to deal with it. I normally easily tear, part of my water works, I don't feel too bad off now it doesn't affect me a lot in a negative way/

Mrs. Y tears up, reports she wishes she did not have dementia, but she does and has to deal with it. She is not aware of negative effects.	She is aware of the diagnosis but not how she has changed.	She grieves for her loss but is not capable of knowing exactly what she has lost.
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I say some of the same things over ask the same questions you know I still read not as much as I did, I can still do the same things—nothing too deep, usually novels./

Mrs. Y recalls that she is aware that she'll repeat comments and questions but states she still does the same things including reading novels, nothing complicated.	Wife recalls that she reads does puzzles in the paper, repeats what her husband said about saying the same things over.	Wife talks about experience within the structure and support of her husband—looking to him for confirmation of what she says.
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[Husband] And the paper.

[Wife] Yes, I still read the paper every day, do puzzles in the paper, and can get the right answers. Ah. . . /

Husband points out his wife also reads the paper which reminds her that she even does puzzles proud she can get the right answers.	She is proud of her cognitive accomplishments.	She is unable to remember what is different relies on her husband's version, holds on to accomplishments.
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[Wife] I don't notice that there a great difference than I used to. Maybe I talk less than I used to. Maybe I'm afraid I'll repeat myself./

Wife reports few differences, states may be afraid of repeating herself.		
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[Husband] What I said before—you're guarded about making those mistakes.

Mr. Y reinforces that his wife is guarded about making mistakes.		
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One thing that I noticed when I suspected this is what's going on is she gets very nervous when someone asks her for information, like when's your birthday? What's your social security number? She just gets rattled./

Mr. Y reports that when he first figured out there was something wrong he noticed his wife would get nervous when asked about birthdate or social security number.	Mrs. Y gets nervous when asked for details.	She has become guarded and sensitive about revealing any cognitive deficits.	She feels shame about her condition and does not want it revealed.
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Switzerland was the very first thing that, she told these people the same story twice and I thought, boy that's unusual she's never done that before you know maybe not monthly maybe semiannually this isn't right./

Mr. Y repeats that after the incident in Switzerland he gradually became aware that something wasn't right.	An initial event led to an awareness that things had changed. He started seeing things through a more discriminating perspective.	This has been a slow development, first noticed 6 years ago.
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And how long after that was the visit to the neurologist? Four years? In the meantime we had talked to the primary care provider, she said make a clock face that and she said you know make a clock face and make it say 5:15 but she didn't finish the rest of the numbers, it said 5:15 she got that part right like um sailboat yacht or what were those words I told you, trouble with those. So she was aware of it started out saying well you have a cognitive problem I couldn't say anything more than that at the time, or she couldn't say more than that at the time she did do an X-ray, I mean a scan, a head scan, you know for a 70-year-old woman it was fine, but we did the psychology testing and she had lots of trouble. Not with the speech part, but the memory, just the memory./

Mr. Y recalls that there were 4 years between the initial incident in Switzerland and the actual diagnosis of probable Alzheimer's by neuro-psych testing. But before that the PCP using a clock drawing test and word recall had detected a "cognitive problem".	During this gradual decline he has been more vigilant aware of the cognitive problem.	He finds some comfort in a logical explanation of the situation.
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Our kids are very aware of this and very supportive. Ah, we could fall back on them if we had to, we don't want to./

Mr. Y reports their children are aware of the situation and available to help if need be, but they would prefer not.	Family is aware and available to help.	It is easier to be stoic knowing he can fall back on family.
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(Wife) I don't know what else to say. Well, I think, I know I don't do as much around the house as I used to I've always, I still sew some, My college major was home economics so I've always done a lot of sewing and our church has a quilting group, so I still work on that I can still do those kinds of things./

Mrs. Y recalls her college major was home economics and how that relates to current activities.	"I can still do..." but thinks she does less. Recalls her background in home economics as a guide to her identity.	Wife is living with the awareness of inevitable decline.	Her losses are accumulating.
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Most of our friends, relatives are aware of it I don't know that I . . .

I think we're pretty open with it you know once she quit the choir she said you know I've been diagnosed with Alzheimer's and it's time to—you know it was kind of demanding she had to go to choir practice on Wednesday night about twenty miles from where we live then they had a lot of special performances other than Sunday so I think it was a wise decision I don't think she missed it/

Mr. Y reports they share the diagnosis with friends and acquaintances' pointing out it was the reason they gave for his wife resigning from the choir.	They share the diagnosis with family, friends and acquaintances.	Her ability to go places and participate required his participation as driver which was demanding.	He is forced into controlling more of her day to day life.
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I enjoy listening to it now./

Mrs. Y responds that she enjoys listening to the choir now.	She minimizes effects of changes.	
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(Wife), I belong to a PO (philanthropic organization) group I went to a meeting yesterday morning. It's one of those if I told you I'd have to shoot you— a ladies group that goes clear back in time there were six sisters, six girls who started this. It's a phi- philanthropic organization; they have a school in Missouri, a college. They support the women who can't go to school they help them out. Still when we lived in Kansas everywhere you go there's a chapter so I've done that I've always been a church goer, I didn't do a lot of teaching Sunday school that kind of thing but I did my share/

Mrs. Y describes another activity she's engaged in giving details and a back-story. Reports she has always gone to church and has done her share of teaching Sunday school.	Hazy about details but proud of her philanthropic work.	Participation and helping others is important for her self-esteem.
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I think I can still take care of myself I, if I need help using the bathroom he'll probably run away from me./

Mrs. Y relates that she can "still" take care of herself and jokes that if she needed help toileting her husband might leave.	She has a pervasive sadness about dealing with the inevitable.	Incontinence is the ultimate humiliation. She fears ultimate abandonment.
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We do what we have to do./

Mr. Y replies that he does what is needed.	He declares his commitment and responsibility to his wife.	His actions are ruled by a sense of responsibility.
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Wife cries.) Sorry my tears—I've had this all my life at times it's worse than other times.

Mrs. Y cries but reports she has always been emotional, cries easily.	She is grieving for her loss.	
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I guess I can say you know she's changed I don't feel like she's the companion she once was there's a small loss of companionship I'd say, but ah, we're getting along./

Mr. Y expresses a loss of companionship.	The changes have led to an altered relationship.	Their relationship has changed and he has a general sense of loneliness.	He misses the person she used to be.
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Um well we have a fairly big house I suppose you could say it's too big for us now but you know, we know eventually we're going to have to make other arrangements for ah living and what will we do, go to a condominium go to assisted living, /

Mr. Y reports current housing situation will have to change.	A change in housing is inevitable.	Thoughts about managing in the future, change of housing.	It is getting time to become aware of housing/assistance options. Trajectory of decline.
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Right now I would say we don't need any help; we have help housecleaners come. As far as food— getting along. If somebody wants to clean the garage that would be okay with me./

Mr. Y reports that they don't really need any household help at this point.	Their life is stable against the understanding of the trajectory of the illness.	They are in a kind of limbo.
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[Wife] I feel like I'm not as essential as I used to be or I don't do as many things as I did before, but I also realize we are retired and I know there is not as much to do either./ He even fixes the meals now. I was a home economics major. I grew up on a farm since I was young. I don't expect him to do all the cooking. He likes to dabble a little bit. We get along fine, that isn't a problem. But I guess sometimes I wish he didn't have to take care of me and I know it's going to get worse instead of better./

Mrs. Y expresses a sense of being less essential, that she grew up on a farm, was a home economics major and now her husband has to fix her meals. She understands they are retired so life is slower but she wishes her husband didn't have to take care of her and she is aware the situation will get worse.	Mrs. Y expresses her sadness at being less essential to their lives, aware of who she was and what she did, knows she is being taken care of and it will only get worse.	Wife has worked hard and contributed all of her life, which makes the current situation difficult to deal with. She is feeling unimportant.	She expresses little self-value in her current state.
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(Here Mrs. Y started crying and I offered to stop the interview but she said, “No I get upset easily he can verify that.” /

Mrs. Y expresses sadness/grief, reports she has always been emotional.		
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[Husband] You are aware I mean I know sometimes when you ask me a question you've already asked— oh I asked you that already so you are aware you do this./

[Wife] I don't always catch myself before I do it (repeat herself).

But, ah, I've never been the type that was sick. I could handle everything./

Husband frustrated by repetitive questions thinks his wife has some awareness of doing this. Mrs. Y reports she used to be able to handle everything.	Her previous coping skills may not be sufficient for current state of affairs.	He is calling upon her cognitive abilities to support diminishing cognitive ability, but she can't help her situation.	He is frustrated by the situation sometimes feeling she doesn't try which reminds her of the way she used to feel.
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She was a school administrator and had a lot of responsibilities different activities going on at one time.

Mr. Y supports statement of wife reporting that she had been in a position of authority with many responsibilities.	Comparison with her previous independence and multitasking skills.	Husband recalls her former independence and multitasking skills, he is grieving for her loss as well as his.	Constant comparison to how she used to be.
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I feel like we're fairly new at this we're in the beginning stages there are people a lot further advanced than we are we've seen the future we know what could happen it could be a gradual progression we hope for that. So do I have any other specific instances? We used to do our own yard work. Courtyard is gravel; we used to do that. This year, we, I don't know./

<p>Mr. Y puts their experience in perspective noting that they are early in the process and have an understanding of possible futures that he hopes for a gradual progression. Points out another change they've made is graveling a courtyard to have less yard work.</p>	<p>Y understands that they are at the beginning of an inevitable decline and hopes it goes slowly.</p>	<p>Mindset of what is to come--husband understands that they are at the beginning of an inevitable decline and hopes it goes slowly.</p>	<p>He wants to hold onto what he still has as long as possible which conflicts with his knowledge of the trajectory of decline and disability to come.</p>
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Do you have any specific questions; are we talking about what's important to you for your study?

If you're done we can stop.

I really don't have anything else.

Is there anything you want to say?

Not really.

Then I will stop this.

Interview 2 Structure

Now he sees life as before and after a specific event. Medical intervention began with medication. Decline led to more medical intervention and a clearer diagnosis. They are able to find humor in their shared experience. Husband has taken on more daily responsibilities as wife becomes unable to continue them. Ambivalence about effectiveness of treatment. They know that the situation will get worse. Wife's identity/ personality is changing, he doesn't know what to expect as time passes. Sense of powerlessness with the understanding of inevitable decline. Wife is aware her husband is making up for her deficits. There have been a role changes. Wife tries to maintain feelings of normalcy by diminishing changes. Changes in his wife are significant, distressing and he isn't sure if it is medication or disease. She is unable to drive herself literally and figuratively. Having to repeat answers over and over is aggravating for him, particularly since he knows she has no control over it making him feel angry, sad and guilty. When he talks about it his perspective changes from the day to day to the entire experience, what it means and how long it has been going on. The "disease" has taken on a life of its own.

"Well the grocery shopping that was another... she used to make a list for the grocery store and it was kind of mapped out according to where things were in the store, like you start here go around there and wind up at the cash register. One time we went and it was just like she didn't know where anything was. So I've been doing most of the grocery shopping here lately, she goes sometimes and she stays, I don't have to worry about her wandering off, anything like that you know things are definitely different but it's hard to really state what they are just realize that's part of the disease?"

He tries to maintain the routine ordinary part of their lives. His wife is unable to be left alone, she requires constant vigilance. Wife tries to minimize and normalize the situation.

He is assisting in the development of social support structures in anticipation of future needs. He is formalizing support structures by assisting in a church program for people with dementia. He manages and schedules both their lives. Mrs. Y minimizes role changes. They are self-conscious and protective of possible slip-ups—they live with the stigma of dementia. She grieves for her loss but is not capable of knowing exactly what she has lost. Wife talks about experience within the structure and support of her husband—looking to him for confirmation of what she says. She is unable to remember what is different relies on her husband's version, holds on to accomplishments. Wife reports few differences, states may be afraid of repeating herself. Mr. Y reinforces that his wife is guarded about making mistakes. She feels shame about her condition and does not want it revealed. This has been a slow development, first noticed 6 years ago. He finds some comfort in a logical explanation of the situation. It is easier to be stoic knowing he can fall back on family. Her losses are accumulating. He is forced into controlling more of her day to day life. She minimizes effects of changes. Participation and helping others is important for her self-esteem. Incontinence is the ultimate humiliation. She fears ultimate abandonment. His actions are ruled by a sense of responsibility. She is grieving for her loss. He misses the person she used to be. It is getting time to become aware of housing/assistance options. Trajectory of decline. Their life is stable against the understanding of the trajectory of the illness. They are in a kind of limbo. She expresses little self-value in her current state. (Not as essential as

I used to be.” Mrs. Y expresses sadness/ grief, reports she has always been emotional. He is frustrated by the situation sometimes feeling she doesn’t try which reminds her of the way she used to feel. Constant comparison to how she used to be. He wants to hold onto what he still has as long as possible which conflicts with his knowledge of the trajectory of decline and disability to come.

Six years ago his wife told the same story twice to the same group of people, which he thought was strange enough to take her to her primary care physician, which led to a diagnosis of Alzheimer’s disease. He laughs remembering they were told the only definitive diagnosis is on autopsy; they aren’t ready for that. They try to find humor in their situation; it is a way of maintaining an emotional connection.

Changes in his wife are significant, distressing and he isn’t sure if it is medication or disease. She is unable to drive herself literally or figuratively. Her personality is changing, she is more dependent, wants him nearby. Her losses are accumulating. He is forced into controlling more of her day-to-day life. He is constantly vigilant, unable to leave her alone for any length of time, he is worried about safety has read about leaving the stove on, wandering. He has to repeat his same answers to her same questions over and over. This aggravates him, particularly because he knows she has no control over it. It’s part of the disease, which makes him feel angry, then sad, and guilty about his response. They are still early in the trajectory of decline; he wants to hold onto what they still have as long as possible. He knows there is a poor prognosis, an average of ten years until death, but he hopes for a slow and gradual decline.

He has gradually taken on more daily responsibilities as his wife becomes unable to continue them. There was no point he made a decision to be caregiver, it happened. They express ambivalence about the effectiveness of treatment in the context of a situation they know will get worse, treatment at best will delay symptoms. While he knows his wife’s identity/ personality is changing, he doesn’t know what to expect as time passes, he has read literature from the Alzheimer’s Association, is familiar with possible stages. He feels a sense of powerlessness with the understanding of inevitable decline, unsure of his ability to manage the situation. He is lonely. He feels the loss of his wife’s companionship. He is frustrated by the situation sometimes feeling she doesn’t try hard enough. He misses the person she used to be.

She is aware her husband is making up for her deficits. She knows she has cognitive deficits but is unable to say exactly what they are. She tries to maintain feelings of normalcy by diminishing these changes. Her husband does more now—but he was always a helper. She is self-conscious and protective of possible slip-ups (forgetting her social security number, repeating herself); she lives with the stigma the shame and grief of dementia. She grieves for her loss but is unsure what exactly she has lost. She was told she shouldn’t drive anymore. In once familiar places, like the grocery store, she no longer knows where things are. It is foreign. Her husband manages all the money.

She talks about her experience within the structure and support of her husband—looking to him for confirmation of what she says. She is unable to remember what is different relies on her husband’s version. She is not as essential as she used to be, a home

economics major in college, managed the house, family and was a school administrator. She could handle everything. She jokes about her husband leaving her if she would need help with the bathroom; incontinence is the ultimate humiliation. Maybe he would abandon her.

He is planning for the future assisting in a church program for people with dementia. They are meeting other couples in similar situations. He finds some comfort in a logical explanation of the situation, reading about the disease and knowing he can fall back on family, his children if need be. He knows that they will have to move from their large house soon, they have a cleaning service now but they will have to move. It is getting time to become aware of housing/assistance options; maybe move to assisted living.

Interview 3

Well just let me say G and I, in September will have been married 64 years and we had a pretty close relationship three years before we were married. And I love, respect, honor her./

Z states that he and his wife have been married 64 years have been very close and he loves, respects, and honors her.	Z establishes the length and relationship within their marriage.	The context, horizon of the current situation is a loving respectful relationship of 67 years.
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We've had a very active life and she was raised on a ranch, my folks lived in town but we had a ranch—also my background is ranching, farming, banking, and I banked for 30 years and during that time we grew our two locations to about 70 and we sold in 1980—the Wells Fargo building downtown Albuquerque we built, and our bank was in there and during this time I was the principal stock holder, the president, the CEO./

Z reports a prosperous life of ranching, farming, and banking during which they expanded the business for which he was CEO, chief stockholder, and president.	Z with wife's help has grown and managed multiple businesses.	They have worked hard and prospered.	He and his wife have been successful partners for close to 70 years.
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And we had many occasions where we had people at our home people here at the facility Albuquerque or other communities around the state that we entertained our customers our stockholders, our officers and people that worked for us and she was always there to help and put on these shindigs which is a lot of effort and we've had over two hundred people at our home in Alamogordo. At our home at the ranch—we lived in Alamogordo when our kids were small. When they got out of college we moved to the ranch, and I left every day and it took me an hour to get to my office in our airplane to get other places in the state and most of the time I flew home at night but we had the strangest life and especially for G. who entertained, and helped me, and was very loyal, and raised our kids. They're great kids./

Z reports that while he was taking care of business, Mrs. Z equally participated in their prosperity by providing their social lives, entertaining their staff, company officers and clients. Z relates his wife was loyal and raised great children. (Establishing deep partnership).	His wife was beside him as partner during their life together and her contribution as mother and social director supporting him and his work was necessary for their success.	They have established a marital unity over time that has supported their life and successes.
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Had one, our son was killed in an airplane crash when he was 17, a freshman in the university here, and that was a very difficult time for her./

Z reports L was deeply affected by the death of their son in an airplane accident.	There was hardship in their life together.	They have managed hard times as well as the successes.	They managed the devastating grief of the loss of a child together.
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She managed that and got over and then at the ranch she loved it and that was the great time and especially after we sold our banking interest and we did everything, we had about 1,200 mother cows and big territory and we worked hard and loved it and had a great life and great family on both sides./

Z says that they both loved their ranching lives; they worked hard and had good family on both sides.	They have had a good life, working hard side by side and prospering.	He is grateful for his long prosperous life and strong family.	His wife was full of life and well connected to him, family and the outdoor environment.
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And the last several years G had a stroke in 2003 and this stroke has affected her walking and her right side, leg, arm and then she has fallen several times from her pelvic bone last time right hip bone and these have taken a toll on her she fell one time and ended up in the hospital about 2 years ago ended up with 14 stitches and on her head and she hit a wastepaper basket, and that was a kind of trying time for her and the last several years she did our bank accounts did our bank statements took care of all the bills she's done all of that, during the last year or so I've taken a lot of that back./

Z reports then L had a CVA leaving her with problems of strength and mobility. L fell, requiring hospitalization. In the last year she has declined to the point she no longer manages the finances as she used to.	Since his wife's stroke ten years ago she has been on the decline both physically and mentally and is now unable to manage some of her previous roles.	A specific event 10 years ago has led to a continuing decline that has changed their role dynamics.	As his wife's health has declined their relationship roles have changed.
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. . .and during this time I went legally blind in 2003. And we've retired. We've moved up here. Our two daughters live in the area and grandkids, now great grandkids. We have 11 great grand kids, and we have a very close knit family, and we've always entertained and loved and we have our family get-togethers as this coming Easter we will./

Z notes that during these last few years he has gone legally blind and they have retired to an independent living facility that is connected to a nursing care center proximate to their children, grandchildren and great grandchildren and asserts he values his close knit family.	His own health is failing they have retired close to their children and a care facility.	Because of his wife's problems, his problems and ageing they have retired to be closer to medical help as well as family.	His health has also declined as they age leading to relocation closer to family.
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And you know L, health wise has slowed down but you know I would never admit that she has dementia but I realize it is in fact and sometimes I feel like a bull in a china closet you know I love her (cries)/

Z finds it hard to admit his wife has dementia, he feels like a bull in a china closet, he loves her and this situation makes him sad.	It is hard to admit the woman he has loved and lived with has dementia. He would like to rage but the situation is fragile.	He resists the label and stigma of "dementia" as a kind of depersonalization. His affinity for her deepens. These transitions to greater awareness of her losses intensify his feelings of loss.
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and sometimes you try to do things right, try to cook try to put... she doesn't like to come down to the dining room and she's never been a big eater but it just seems like it's hard to fix things that she likes or do things that she likes sometimes you mention something and maybe she's forgotten about it has not thought about it lately for instance I mentioned to a lady that has grandkids that maybe they could come to our storage area and help me I've got a lot of old records that I need to put through a grinder or what you call and get rid of and it upset her in that it kind of shocked you and surprises you and she you know you just feel you want to do things right and a lot of things are right but sometimes you know when she won't eat ah it doesn't... maybe want to do something with the family or close friends we have left and maybe she has something/

Z reports examples of how the effects of dementia make it difficult to keep his wife happy and keep from upsetting her, The situation is unpredictable.	His wife's symptoms make it difficult to please her.	Communication of love and tenderness has become difficult. His wife's symptoms make it difficult to please her.	He tries to identify her mental states to achieve some traction with her personhood and hold on to their couple identity.
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She is not completely well maybe you never get over a broken hip and walk like you used to, and her foot from the, when she had the stroke like her right foot is turned in and it's just difficult she has to put her right foot out like that to keep from dragging it on the floor/

Z states that his wife hasn't physically recovered from her stroke.	Mobility problems persist as well.	Her physical problems are obvious.
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And she is, she feels like maybe she doesn't want to be in crowds and she doesn't want to slow down she has a walker and wheelchair but it's difficult for her that she was so active/

Z reports his wife was very active and is having difficulty slowing down as a result of the residual problems since the CVA, and doesn't want to go out as much.	He thinks his wife is withdrawing as she compares herself to her younger days.	He imagines what she is thinking and feeling, what it would be like in her place.	Identifying mental states of growing isolation and persistence/ stubbornness.
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She rode with us on the ranch just like any other cowboy and helped, kept our records all of our calves had ear tags and records at branding she kept those records up and now she you know can't do all that and it's frustrating for her to realize that and accept that,/

Z remembers how full his wife's life was both physically and intellectually and suggests she must be frustrated as she is no longer able.	He thinks how frustrating that kind of comparison must be for his wife.	He has difficulty reconciling her past experience with the current situation.	Identifying her mental states of frustration, resisting acceptance of the situation.
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and let me—she'll come into our kitchen in our apartment here and she gets her walker in there and neither one of us can move but she wants to help yet she, you know, she needs my help too and ... Well she can't stand too long by herself or with cooking things and in, I can reach without my machine and you know some of the papers from the hospital she likes to see—go through and understand them but then, she, the communication with the doctors with the hospital with the doctors and the facilities, I need to do for her but she does not hear good anymore and its very disconcerting with her on the phone she doesn't understand people and so I make a lot of phone calls for her and I give her *her* phone and use mine, and ask if it's all right I talk to her, and that kind of helps. She needs, and she, she's concerned—/

Z says his wife resists his help but knows she needs it, he finds ways to assist her in her efforts without taking over the entire task	His wife's struggle to maintain her independence makes day-to-day life more frustrating and difficult for him. It would be easier just to do what she needs done than waiting for her to do it herself.	Supporting his wife's ongoing assertion of her independence makes life more difficult for him.
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We don't have financial problems, but she likes to have quite a bit of money in the bank that we don't need, but just for safety reasons she she's concerned you know our family is fine but when we have other guests in the apartment well she isn't really comfortable anymore with that and so we don't, maybe once in a while/

Z notes that his wife possibly feels worried and insecure since she wants to keep money in the bank even though they are financially secure, she longer likes entertaining at their home; it makes her uncomfortable.	His wife has new emotional worries, shoring up home security and avoiding social situations.	His wife has become less comfortable in social situations, more insecure about money.	His wife has withdrawn more from social interaction and needs physical representations of security.
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She just isn't comfortable, she's, she just you know and we invite a friend to come and have dinner with us she'll do it and I do it but it' just harder on her to accept that sort of thing and in the past you know we've had lots of people lots of things going on and, and she's—it's tough for her now and it you know I, I love her more I've tried harder but it's a tough job to be caregiver and comes the oxen at the same time/

Z knows his wife has changed; ordinary activities make her uncomfortable, considering the woman she was he feels love for her even stronger, but it's hard for him to watch.	It is tough enough to be the caregiver, it is even harder to watch the woman he had known and loved change so dramatically to the point previous enjoyments are avoided.	He loves her more, feels closer and tries harder but feels ineffective in making any headway. The physical care is insignificant to the way dementia assaults her personhood.
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[What does that mean?]

Well you're not I'm never I cook the kind of stuff I like, like ranch and Mexican food after I retired I did a lot of canning just for fun and but I don't it's hard for me to make up menus to come up with stuff she would like to eat and she was a picky eater.

Z explains that for example, with cooking, his repertoire is limited, his wife was always a picky eater and now she is more so. (Comes the oxen = additional load?)	Cooking and meal planning is a new skill he has had to develop. Finding food his wife likes is difficult.	The psychological work of predicting what will comfort her is as hard as meeting her physical needs.
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The only time I did the cooking was well like out at the ranch we would camp out in big canyons say 5000 feet to 10,000 feet this canyon and we had a fence at about 70–75,000 feet and we would gather cows in spring we would put them through and camp there maybe 4 days and cook in Dutch ovens and ride all day long and she was right there with us then we'd go home and clean up and get ready for the next canyon but she was capable of doing all of this, enjoyed it and now she isn't and you know she I feel like she will again be able to cook some stuff stand there be able to cook in the kitchen by herself but like she used to/

Z says that the only times he used to cook was when they were up in the canyons rounding up their cattle, and his wife was right there and could do it as well but now can no longer do any of that, but he hopes and imagines a time when she will be able to do it again.	He contrasts present cooking difficulties with days in the past they rode together and cooked outside. Holding on to those memories helps manage the present.	She is unable to conduct life activities that she enjoyed in the past.
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And, and I know that she gets agitated because she can't do that and wants to help me but in our little kitchen there isn't room so I tell her its best that you do it or me and we won't be running over each other and we she does it her way and I do it my way she'll come and clean the sink and the counter while I'm there cooking and it's just hard to do it and keep smiling not that I, I appreciate the opportunity/

Z knows his wife gets agitated from the frustration of no longer being able to do what she's done for so long and he tries to accommodate her need to help but sometimes in their small kitchen it's difficult for them both to be there, and for him to keep smiling.	Although he understands his wife's frustration with being unable to continue her roles as they used to be, he becomes frustrated because the role tasks need to be completed.	His wife's help gets in the way of daily chores. Both are frustrated.	Their transition to different domestic roles is difficult almost symbolic of giving in to the set of circumstances.
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And we could certainly afford to have someone come in and do it but I'd rather do it the way we are and we made up our minds if we become sick and on the way out we want to stay in

the apartment and we can have help come in and Daisy but in the mean time we want to stay out of the nursing home and hospital /

They could pay someone to come in and housekeep but he prefers the way he's handling it. They want to stay in the apartment and if needed in the future they will get health care assistance to stay out of nursing homes or hospitals.	He knows he can relinquish some responsibilities completely but he wants to maintain their living as closed to the way it was as is possible.	Neither of them wants to die in a nursing home or hospital.	They want to support and be with each other until the end of their lives.
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I appreciate the opportunity to take care of L. Taking care of L, it means my whole life. You know, we've always had a good relationship and to try to keep her going (and I have a cough drop) I, but anyway it's a different part of our lives and we have so much to be thankful and to our lord and our family we have a great family and they are so good to us./

Z says he and his wife have shared a long good relationship they have so much to be thankful for and now they are at the end of their lives and taking care of L enriches his.	The opportunity to love his and care for his wife in the present situation is the culmination of a deeply blessed life	He recognizes he is approaching the end of life and wants to do it his way.
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[I ask what he meant earlier by not wanting to admit L has dementia.]

I know it's, my mind isn't what it used to be, my memory is certainly not what it used to be and ah you have to accept it and I know we have to accept that but it's all right you know I don't want to feel like Glenda thinks she has anything wrong with her/

Z says his mind isn't what it used to be either and he doesn't want his wife to feel deficient.	To him "dementia" suggests a deficit in his wife and he does not want to look at the situation in that way or have his wife feel deficient.	Dementia is something that comes along with aging, that you can't control but he doesn't want to feed its stigma.
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Well I think it bothers her and when I do certain things I don't mean to. Just like we send every one of our grandkids their children and wives 50 dollars for their birthdays, and she's done that and I've had to start doing that and it makes her feel you know, not, well like I'll do that but you have to get it done by certain days and I just know she feels like, "well he doesn't think I can do that," and you know sometimes I've tried to discuss those things but if I do it and don't let her know or she forgets she feels like maybe I'm taking over her duties and her responsibilities.

Z thinks his wife is bothered when he unintentionally takes over roles that were traditionally hers. He has tried to talk to her about it but she either forgets or is resentful.	Direct communication about the situation is difficult due to resentment and or memory lapse.	Their relationship is at odds due to her suspicion of his motives.	He is learning new patterns of action to avoid her wrath and maintain his responsibilities.
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I have been taking over her responsibilities, but I have to, you know we have to keep everything going and you know those 20 some odd birthdays every year and at Christmas we do the same thing and you got a big family and you know we stay in our ... grandchildren have been so good to us our two grandkids and their three kids are in Spain they were in Okinawa they came by for half a day on the way to Okinawa and Spain and we have a family of six north of Fort Wayne, Indiana and you know we talk to them on the phone and wrote to them and the gal who lived with us with her mom and sister for several years our granddaughter and her mother and sister anyway there's a lot of those things that need to be done and its, L knows it and feels like, "I should do that but I'll do it tomorrow." And if I go ahead, but I try to do it, write a card or ask her to sign it with me, just those family duties that we have—anyway it's just, it's hard./

Z says that he has to do this even though he knows it bother L., because they have a large family and responsibilities. L will say she's going to do them but she forgets, so he tries to involve her, doing it together.	An important role he is taking over is the maintaining of family connections and remaining engaged and involved.	She cannot maintain her previous duties but is resentful when he steps in.	At times he is torn between responsibilities of the outer world and his wife's changing inner world.
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It's just, to see a person with such a great mind a great life so many things and all of a sudden she can't do some of those things, she can't find where it is, and I'm no help because being blind you know I have to take a file out of the cabinet and put it under my machine and if it's the wrong file then it's a mess it takes me about ten times more time to do things and it was just automatic, /

Z says it is difficult to watch her change from a woman with such a great mind and life to her incapacity and this is exacerbated by the difficulty his blindness presents when trying to help her.	His wife has gone from a woman with a great mind who automatically managed the details of daily living to someone who can't identify the details.	He can no longer rely on his wife's support and insight, his wife's emotional behavioral challenges his view of the life world.
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I don't feel like I've done a real good job, but I feel like I've tried, and we, we don't have many cross words/

Z doesn't feel like he has done a really good job, but most of the time he manages to maintain harmony.	He is doing the best he can to maintain harmony between them.	It has been a tentative negotiation of who they were and who they are and what is important in life.
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But then just once in a while she'll be shocked like when I went to get rid of part of the storage. You know I thought she'd be tickled to death too. We talked about it the last few years—you don't want to leave all that junk there for your kids to mess with and I don't know we've we're still best friends we don't argue I never have I just don't believe in that./

But Z points out on the other hand there are many examples of when he can't keep the peace; He is stuck between keeping her happy and doing what he has to do. They have never been arguers, he doesn't believe in it.	His wife's dissatisfaction is unpredictable and at times provoked by his making decisions she doesn't recall having talked about. He is trying to maintain the connectedness of their long relationship.	He still becomes shocked when he realizes how far apart their world views are.
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I know that sometimes I worry to death trying to get her to eat something and some days its only one little meal and I mean little and I've tried smoothies whey protein in them try to make them healthy./

Z says he worries so much at times when he is unable to do what he thinks he should, like getting L to eat, he has tried different strategies to provide sufficient nutrition.	He knows the goal but not how to achieve it.	Even tasks like feeding become battles of oppression/control and resistance.
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She is 82 and I'm 84. She was 19 when I was married. Well I think we're better friends now then we were when we were kids, when we were first married, the world has changed we've had our differences in the past. But not great big differences and she's done a tremendous amount of things. After our son was killed I had this fellow who came to me and wanted to be my partner in building an antique shopping center in Alamogordo, was part of the railway hotel they built in 1898. I didn't have any time and this was after Beau was killed, and when he started to leave, he was a good friend and artist and I did buy a lot of his paintings for banks and our home, and I said you know what you come to our home tonight and you talk L. into being your partner and they built that a gallery it was real nice well, a famous artist and she, they had a large dining room and they built all the furniture and it was all rustic Mexican style and little shops and Glenda had a little shop in there she had books and gifts and the jewelry and things like that and one time we leased it to this young couple they did a great job worked themselves to death just wanted to serve dinner and Glenda thought it was important to the shopping center to serve lunch so she kicked them out until they leased it to someone else she never joined those clubs. She was busy doing what we were doing and the chef couldn't boss so she would make salads and desserts at home. I'd come home and there would be 100 odd desserts all over the kitchen and she'd be in the kitchen and you know she did a nice job of managing that. Then the fellow left and moved to Santa Fe and it was good for her working having a project /

Z says he is 84 and L is 82, they married when she was 19 and they met when she was 16. They had a difficult time in their marriage after their son died in a car accident. He facilitated a project for her which she accomplished, by working hard	They have been partners through tough times in life.	He recalls his son's death in the context of "having differences" in the past how they worked through it in their own ways as explanation for their differences now.
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And that was after Beau's death and anyway you know it's not always easy to get old and a little decrepit with it/

Z says regardless it is hard getting old and decrepit.	Ageing is a process of diminishing abilities	
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And it's you know maybe I had Norman Vincent was my mentor and all 700 of my employees took Dale Carnegie courses and we owned the lodge in Cloudcroft the ski area the golf course and sometimes we were the only local partners, and ran it, she did mostly. We've had a very active life and then you get down where you can't do those things and it's frustrating and she had to give up her car in December and she probably didn't—her car was 5years old, didn't even have 10,000 miles on it and most of those miles were trips to drive us to Ruidoso to the grocery store. So it's not like we were used to going honky-tonking but it's you know all of a sudden and I haven't been able to drive for 2 years and you get if you have to do something you know get batteries do this or do that once in a while and our kids and grandkids are good, but you get to that point where you, well you don't—some of our friends we haven't seen in a long time they're so old and you know I tell L I have 22 more years to go and I've always been positive thinker and I believe in that and then when you do things and you think you're an old son of a gun it's hard to admit./

Z keeps a positive attitude, his wife was very accomplished they've had a good life together; it is frustrating getting old, becoming dependent and losing friends.	The current situation is against a backdrop of old age and decline, awareness as well as resistance to the situation, buoyed by attitude.	
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Same for her for me: I love her I'll say that I love her more now than ever before and I think vice versa and we thank the lord for that great family that is ours and we feel pretty happy and pretty responsible.

Z projects that his wife feels the same way they love each other more than ever and they are thankful for their lives.	Regardless of his care giving struggles, he knows his wife loves him as he loves her and is grateful for their lives.	His love/affinity for his wife has increased as they have both become more dependent on others. Sees this in context of their whole life together. Meaning is a choice of attitude.
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Interview 3 Structure

The context, horizon of the current situation is a loving respectful relationship of 67 years. He and his wife have been successful partners for close to 70 years. They have established a marital unity over time that has supported their life and successes. They have established a marital unity over time that has supported their life and successes. They managed the devastating grief of the loss of a child together. His wife was full of life and well connected to him, family and the outdoor environment. As his wife's health has declined their relationship roles have changed. His health has also declined as they age leading to relocation closer to family. He resists the label and stigma of "dementia" as a kind of depersonalization. His affinity for her deepens. These transitions to greater awareness of her losses intensify his feelings of loss. He tries to identify her mental states to achieve some traction with her personhood and hold on to their couple identity. Her physical problems are obvious. Identifying mental states of growing isolation and persistence/ stubbornness. Identifying her mental states of frustration, resisting acceptance of the situation. Supporting his wife's ongoing assertion of her independence makes life more difficult for him. His wife has withdrawn more from social interaction and needs physical representations of security. He loves her more, feels closer and tries harder but feels ineffective in making any headway. The physical care is insignificant to the way dementia assaults her personhood. The psychological work of predicting what will comfort her is as hard as meeting her physical needs. She is unable to conduct life activities that she enjoyed in the past. Their transition to different domestic roles is difficult almost symbolic of giving in to the set of circumstances. They want to support and be with each other until the end of their lives. He recognizes he is approaching the end of life and wants to do it his way. Dementia is something that comes along with aging that you can't control, but he doesn't want to feed its stigma. He is learning new patterns of action to avoid her wrath and maintain his responsibilities. At times he is torn between responsibilities of the outer world and his wife's changing inner world. He can no longer rely on his wife's support and insight, his wife's emotional behavioral challenges his view of the life world. It has been a tentative negotiation of who they were and who they are and what is important in life. He still becomes shocked when he realizes how far apart their world views are. Even tasks like feeding become battles of oppression/ control and resistance. He recalls his son's death in the context of "having differences" in the past how they worked through it in their own ways as explanation for their differences now. Ageing is a process of diminishing abilities. The current situation is against a backdrop of old age and decline, awareness as well as resistance to the situation, buoyed by attitude. Regardless of his care giving struggles, he knows his wife loves him as he loves her and is grateful for their lives. His love/affinity for his wife has increased as they have both become more dependent on others. Sees this in context of their whole life together. Meaning is a choice of attitude.

He and his wife have known each other for close to 70 years. During this time they have had an incredibly interesting and rewarding life that has also led to many financial successes. Now they are old close to the end of their lives. He married the girl next door and feels blessed to have met and married her and loves her even more now that her health and mind are failing and she needs him. When they retired they moved from their rural expansive ranch that holds memories of cattle roundups and camping at night, to a senior

living facility to be closer to their children and medical care. Ten years ago she had a stroke and since then she has struggled physically and mentally; she is unable to stand for any length of time and can't keep up with the checkbook or their correspondence. He knows that she really hates and resents becoming dependent. He knows she is aware of her memory and thinking ability failing. He knows she has dementia but this is a horrible thing and really a nasty word, it leads to depersonalization. They are both getting older; his health has also declined as they age; he is blind, his memory isn't what it used to be either.

She used to like company and entertaining but now prefers isolation. She is persistent and stubborn she wants to walk without help, continue her previous responsibilities. This adds to his struggle of care giving because certain things have to be done at certain times and waiting for her to do them doesn't work. And then she gets angry accusing him of having no trust in her. She is frustrated, resisting acceptance of the situation. She has withdrawn more from social interaction and needs physical representations of security—cash in their checking account even though they have no financial worries. She is unable to conduct life activities that she enjoyed in the past. She no longer drives or can go anywhere without her husband's assistance, and he is blind so they depend on their children, friends, employees of their senior living facility, she is trapped.

He tries to identify her mental states to achieve some traction with her needs to keep her comfortable, reasonably happy. At times he is torn between responsibilities of the outer world and his wife's changing inner world. Supporting his wife's ongoing assertion of her independence makes life more difficult for him. Even tasks like feeding become battles of oppression/ control and resistance. He can no longer rely on her support and insight, because his wife's emotional behavior and view of the world is different. She is delusional and gets angry for reasons that aren't real. Sometimes he is shocked at how differently she sees things. He is learning new patterns of communication to avoid her wrath and maintain his responsibilities—he handles her. It has been a tentative negotiation of who they were and who they are and what is important in life. He loves her more, feels closer and tries harder but feels ineffective in making any headway communicating with her and sharing their long established companionship.

His frustration and grief is palpable, he feels like a “bull in a china shop.” He has learned to manage the physical care but the emotional upheavals and personality changes are almost unbearable. They want to support and be with each other until the end of their lives. Regardless of his care giving struggles, he knows his wife loves him as he loves her and is grateful for their wonderful lives.

Interview 4

Like I told you over the phone we've been married over 47 years, 47 ½, I guess. We've got four kids, all adults. Three grandchildren um we've lived here in Albuquerque 27 years I was in the Navy for 25 years before that so this is where we chose to retire and everything seemed to be going along fine and pretty normal, /

A reports background information: he and his wife have been married 47 ½ years, they have four adult children, grandchildren, they retired to Albuquerque after his service of 27 years in the Navy, life was fine and normal.	They had over 47 years of marriage and family life.	After 47 years of normal family life and retirement the situation changed,
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Until it was October of 2011, a year and a half ago. One day she said she didn't feel well and was acting strangely and disoriented in a house we lived in for many years, 27 years. She couldn't find her way around, didn't seem to know what was going on, so I took her to emergency and they diagnosed her with delirium and kept her there a few days 'til her head cleared up so after that we started seeking medical help and we first went to our primary then we went to a neurologist who gave her an additional diagnosis which amounted to vascular dementia and she in turn sent us to Dr. ___ who does neuropsychiatric exams, a psychologist I believe here in town who did a half day exam of all the psychological tests they do and decided that she was suffering from moderate vascular dementia and that put us on a course of action to deal with that.

A says in October of 2011 is wife started acting confused disoriented to a house she had lived in 27 years, prompting an ER visit. His wife was diagnosed with delirium. Soon after, they went to a neurologist who referred them to a neuropsychologist diagnosed vascular dementia.	Routine life was interrupted by an episode of disorientation that eventually led to a medical diagnosis and set them on a trajectory.	Their normal lives were interrupted and set them on a new life course focused on medicine and dementia.	A particular event marked the change. His wife found a very familiar environment foreign. A medical diagnosis of dementia changed the focus of their lives.
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The neurologist noticed from one of her brain scans she also had some plaque in the brain she referred to as ischemic white matter disease, which she said, was consistent with this diagnosis./

A says that according to the neurologist a brain scan supported the diagnosis.	Physical data supported the diagnosis.	
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So since that time we've seen a psychologist up at P, we continue to see the neurologist, and have since been referred to a psychiatrist who is treating her now, she's had some pretty

severe depression that went along with the dementia. At times the dementia has been pretty noticeable and other times it's been pretty mild to non-existent for several months. And now she's back in a period I think the depression is the most pronounced symptom were dealing with now./

A says that since the diagnosis they have continued to see the neurologist, now see a psychiatrist and a psychologist as well. The dementia symptoms fluctuate and are exacerbated by depression.	The symptoms fluctuate and the diagnosis is not straight forward but complicated by other factors.	There is no predictability to the situation.	His wife's emotional responses are at times more concerning than the dementia.
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In general she knows who she is and who we are and can remember most things, but she is just generally depressed, he's treating her for that, more recently she started to get confused again particularly in the morning. Sometimes she will have had some pretty strange dreams and they carry over into reality for her. A couple of times in the last ten days she's woken up in the middle of the night just hallucinating absolutely sure the house was falling down, absolutely sure the bed was going to fall through the floor and she wasn't going to get back into it and we had to go sleep in the guest bedroom./

A says that for the most part his wife is oriented to people and places and can remember most things but recently she gets more confused in the mornings, possibly hold over from dreams that confuse her reality and scare her.	There is wide variability with respect to his wife's awareness of details of current states of affairs.	He must be vigilant all the time because she is not safe without supervision; she is at times irrational and acts upon delusions.
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I think that maybe related to some news stories recently about the event in Florida where the sinkhole opened up and swallowed some man in his bed but you can never be sure. She's put that aside well those are some of the, I guess psychological manifestations /

A thinks there could be a rational explanation but he isn't sure. He describes these as psychological manifestations.	His wife's responses can be irrational.	
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For years she suffered from almost chronic headaches she used to have migraine headaches, she complains almost daily of stress headaches they begin in the back of her head. Almost every morning first thing when she gets out of bed when she gets up out of bed almost the first thing she wants is a pain pill. We have several that I rotate around so she doesn't get too much of one. It doesn't matter to her so much what she gets as long as she gets a pain pill and she is kind a fixated on that all day./

A says his wife suffered from migraine headaches and now she complains of stress headaches for which she asks for pain pills every morning and she is not particular about which pain pill.	His wife is focused on her physical body and interacts with respect to this.	All day his wife has complaints that he must address.	He must be responsive the entire time he is with his wife 24 hours a day.
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She's on a lot of medications for blood pressure and thyroid and cholesterol what else --she's taking both Aricept and Namenda, she's on a new antidepressant called Mirtazapine I think. Um I've lost my train of thought, anyhow that's been a constant thing for a long time she just never seems to feel very well between dementia and depression she has a hard time getting interested in anything anymore./

A says his wife has medical problems and is taking medications for those as well as dementia and depression. He reports she has no interest in anything anymore.	His wife is on multiple medications yet never seems to feel well and has few interests.	He manages his wife's medications for dementia, depression and physical problems and still she is never really well, and usually lacks interest.
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She used to be very active, in fact for about 10 years she worked as a volunteer over at X hospice, she loved that, she can't do that anymore so she remains fixated on her, instead of things around her Its fairly typical as I read the literature some of the things she's going through./

A says there's a big change in his wife compared to the time she worked as a hospice volunteer for 10 years. Now she seems fixated on herself. A thinks that is typical judging by the literature he has read.	There is a significant change from the emotionally invested, active woman she used to be, to someone focused on herself.	She used to enjoy life and have many interests now she is like a different person, focused on herself.
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She doesn't want me to be far away and yet she gets pretty irritated and angry with me when I'm around, I'm Dr. No, the bad little guy that sits on her shoulder and tells her she's gotta do that and she can't do that and so she reacts to that typically she perks up when someone new, when there are other people around the house./

A says that his wife needs to be around him but resents his constant instruction. When someone else visits she generally perks up.	He knows his wife wants him close at hand yet his intervention frustrates her. She perks up when someone else is there.	He finds himself in a disciplinary/safety mode that is necessary but aggravating to his wife. At the same time she wants him nearby.	His role has become parental, looking out for her health and safety. She is ambivalent towards his presence and enjoys visitors who give her a break from him.
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We have a couple grown daughters who give me a break she reacts pretty well with them. We have other friends of course when they call she's pretty up beat. /

A says he has grown daughters who give him respite and the welcome interruptions of friends.	His daughters or wife's friends offer respite for him and diversion for her.	She must always be supervised.
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And so it's just for some time now she hasn't been eating well, I have a terrible time getting her to eat. I ask her what she wants, we negotiate something she says she'll eat, I fix it she takes a couple bites and says she doesn't want it any more so she's lost a lot of weight she didn't need to lose. She isn't very big 5 foot. She started out around 125 now she's down to 103 or 4 around there. Everyone tells her she's gotta eat and drink more but she just can't. So it's frustrating in that sense. I keep trying to find the right combination that will make her feel better. She seems almost determined not to do it. I don't expect it's something she's doing deliberately. I think a combination of dementia and depression but she wants to sleep all day so it's hard unless we're going to a doctor's appointment to get her up, to get her to eat and drink enough so in a nutshell that's where we are.

A reports that feeding and weight loss are issues of concern. It seems a constant battle.	Providing sufficient nutrition and appealing meal plans are a constant struggle since his wife seems to deliberately resist his efforts. Although he knows it is her illness the situation is frustrating.	Ensuring her adequate nutrition has become a power struggle.
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I pretty much do everything. She, depending on how she's feeling she can go to the bathroom and take her shower, sometimes I have to take care of that, but I do all the cooking and personal care, /

A reports he takes care of household duties as well of most of his wife's personal care, at most she occasionally takes a shower herself.	He completely manages their lives including his wife's personal care.	He provides custodial care for house and wife.
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We do get some help we have a housekeeper who comes in every other week that's why I can be here, she'll stay with her talk to her and generally be very pleasant; and we've got a home-health aide who comes from C, she comes in every Friday morning, I'm looking to increase that kind of help but she likes this lady that comes so well that she's just not available on other days right now I'm reluctant to bring in a second one I'm afraid it might disrupt the relationship and she would not understand what I'm doing but she does get out nearly every week for a hair appointment a beautician she's gone to for many years and they're very close so I can usually drop her off there for a couple hours Thursday morning go get my grocery shopping done that kind of thing, Every Friday I've got some time /

A reports that they have housekeeping help, a woman his wife likes and will talk to, he can leave them together. He also has a health aide that they both like; he would like more of that kind of help but worries that if it's an additional person it could confuse his wife. He also leaves his wife with the hairdresser she's been going to for years. Every Friday he has several hours free.	He has relief help from a housekeeper and a home-health aide, and weekly hair appointments with a beautician his wife has known for years. He doesn't want to disrupt these established patterns and relationships.	There is a delicate balance to the situation and support relationships, he feels like introducing more people would confuse his wife.
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It seems like we have 2 or 3 doctors' appointments every week. I've gotta say the medical folks we've been dealing with are very good the primary care were using now is a nurse practitioner named K at T she's really super she's taken a personal interest and does anything everything anybody could and the other doctors we see are good I don't have any complaint./

A reports weekly visits with the medical community and has no complaints about the care they receive.	He takes his wife to medical appointments weekly, the medical providers seem to take personal interest in their situation, but there isn't much that can be done.	
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N on the other hand feels that since she hasn't had a rapid transformation that there's somebody out there who could turn her situation around and they just aren't telling her.

A reports that his wife is not happy, that she thinks there is help she isn't being told about.	His wife feels there is help she is not getting	His wife thinks that real help would change her situation.
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She knows—in fact when we had this psych eval done, which was just a year ago now, she came away from that relieved. She just didn't want to have Alzheimer's. She just sees that as more threatening ah that in practical terms I don't think there's much difference, but it was comforting to her that she had a different diagnosis./

A reports that his wife is aware of her diagnosis and in fact was relieved not to have Alzheimer's, that she considers that more threatening.	But she was relieved when told she did not have Alzheimer's.	There is more stigma to Alzheimer's dementia his wife was glad she doesn't have that.
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And uh a number of times when she hasn't been doing well first thing she says is she wants to go to the hospital, "Take me to the hospital" but she doesn't want to go to the hospital she's hated that, "Well but nobody's helping me, take me to the hospital" and then it gets to "Well just take me to a nursing home and forget about me." /

A says that particularly when she is having more difficulty his wife gets frustrated and wants to go to the hospital because she feels like she is not getting any help even though when she does go to the hospital she doesn't like it. Then she may request to be left off at a nursing home.	His wife will insist on going to the hospital because no one is helping her but he knows that when she has gone to the hospital she hasn't liked it. She sometimes demands to be left at a nursing home.	His wife's frustration leads to her emotional and contradictory demands.	His wife's contradictory demands make her impossible to please.
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As part of the background to that we too, were primary caregivers to her mother for several years before she died and her mother did end up in a nursing home before she died, she was 93. N used to go up there she had several sisters here at the time they would take turns she would go up there just about every day to help feed her and make sure she was okay and she had great frustration about how the nursing home was being run and so I remind her of that, that—"No you don't want to go to a nursing home just yet."/

A states that he and his wife were primary caregivers for his mother in law who did reside in a nursing home before she died. His wife was unhappy with the care there. He reminds her of this when she makes comments about just dropping her off there.	He knows his wife's opinion of nursing homes because her mother ultimately was in one and his wife had great frustrations with the placement.	He tries to address these contradictions with rational argument.	"Nursing home" has the symbolism of abandonment.
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And then every once in a while she says "I just want to die I don't feel good." In fact yesterday we were sitting there at the table and just out of the blue she says, "Do you want to divorce me?" I assured her no, I didn't. She is concerned she's being a burden, still she still is fairly demanding most of the time./

A says his wife often says she just wants to die, is concerned he will leave her yet still is demanding most of the time.	His wife wants to abandon life, is afraid she is a burden and he will abandon her, seeks reassurance, and yet is very demanding most of the time.	His wife is frantic with her sense of being a burden.
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Sure it's an extra load but it's what you sign up for—for better or for worse/

A sees the situation as burdensome but part of the responsibility and duty of marriage.	He made a commitment.	His sense of responsibility requires that he take on the work.
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And uh, well I guess one of the things that's difficult is, like in one sense living alone because there isn't much communication anymore; she spends most of her time either in bed or on the

couch sleeping. She watches television sometimes. She doesn't have a lot of interaction anymore. She's always waiting for me to tell her the next thing to do. She asks my permission for almost anything she wants to do. "Can I do this? Can I do that?" and so, as I said,, she gets impatient and angry sometimes with me because I do have to give her so many directions and at the same time she doesn't want me to be far away and so I guess the main thing is being there alone, except I have to do everything that has to be done. That's not a great burden. I don't have to go to work. It's just that it's day in and day out the same kind of thing./

A feels like he is living alone because there is little meaningful communication between them, yet the day-to-day monitoring of his wife is non-stop. She asks permission for almost everything she wants to do yet she resents being told what to do.	He is lonely with loss of companionship. Most communication is directives.	He misses the companion his wife once was.	Loss of companionship and the sameness of day-to-day living are hardest for him.
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We used to travel quite a bit we've got a trailer that's pulled by a truck we used to do that I don't know if we'll get to do that again so it's just a lot of things that we used to do and we can't do now it's always possible too that she'll perk up again and feel like doing some of that stuff again but the its awfully hard to make plans, /

A says they used to enjoy traveling with a travel trailer but he doesn't think they will be able to do that anymore yet holds onto some hope the situation will change.	Many things they used to enjoy are lost.	Their routines have become restricted to the custodial.
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We did, the first two weeks of February we did take a trip out to Palm Springs we me my sister and brother in law there they've got a time share condo thing out there invited us to come out and stay with them we were out there about 10 days she did pretty well on that, but again, there was my sister would get her up and out go shopping she was in pretty good spirits to eat she did pretty well but when we were around the condo or she didn't have anything to do she just wanted to sleep then she wanted to go home several days before we were ready to go—I want to go home, I want to go home./

A says that the last time they traveled was 2 months before this interview, they visited family and his wife did well with directed activities, like shopping with her sister in law but when they were in the condo she would get restless and want to go home.	They traveled recently to visit family. When participating in directed activities his wife did well, but otherwise wanted to go home.	Activities that used to be fun are more work and less fun.
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Since we've been home a little over a month, she, in general, has been pretty depressed and not much interested in doing anything that's about the, descriptively what I can tell you about what's going on./

A says that since their return his wife has been depressed and apathetic.	When his wife lacks energy or interest it is more difficult for him to get through the day.	
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[Is there any aspect you feel particularly good about?]

No I can't say I feel particularly good. It's a just a daily set of chores we have to go through. I have to get her up in the morning, that's not easy. She doesn't want to get up usually and uh, and so unless we have to get to an early appointment, it's usually between 10 and 11 before I'm able to get her up and get her morning meds and some breakfast and then she'll want to go back to bed. In fact, even when we're trying to get breakfast she'll get up and say I want to go lay down awhile so most mornings are unless there's someone there like the housekeeper or the health aide are pretty well shot just getting her moving and then she'll want to sleep most of the afternoon we usually have dinner around 5:30 or so she just usually isn't too much interested. I think she should eat. "I just can't eat anymore" or she has to go to the bathroom and then doesn't want to come back to the table so it you know just kind of wears on you after a while wish you could be doing something that made more of a difference I don't see that things change much./

A doesn't find any part of the situation rewarding it is one chore after another nonstop, she doesn't want to eat, only sleep and he feels his efforts are fruitless and don't make a difference. He doesn't anticipate this will change.	The work is physically and emotionally difficult and doesn't seem to make a difference in her response and he doesn't see that this will change.	His days consist of a series of emotionally and physically demanding tasks that don't seem to make a difference to his wife's wellbeing.
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But I also understand that it's pretty much the way dementia plays out over time./

A understands that his experience is consistent with the course of dementia.	He finds some reassurance that his experience fits a known pattern.	
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I don't want to think about putting her in a home as long as she knows who she is and who we are and is responsive I hate to think of her having to go to any kind of institutional home, /

A says he doesn't want to think about putting his wife in institutional care as long as she is aware that she is being cared for by family.	It is important that his wife is aware of his efforts.	Institutionalizing represents a kind of abandonment.
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... financially it wouldn't be a big problem for us (laughs) she's always been kind of a worrier and someone who's wanted to have things planned out in advance she got me several years ago to get some long-term care insurance. We've had it for like 10 years and it's a good policy and now it's paying off for us. If I had to put her in a home it won't cover the whole cost of course, but it would pay a large part of it so financially that I'm not looking at a big—

He laughs at the thought of his wife taking out long term care insurance about ten years ago, describes her as a worrier.	His wife had taken out a long term health insurance policy about ten years ago.	His wife has taken out long-term care insurance so if he decides on this course she has already made it easier.
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It's just (tears) Excuse me. I just don't want to face that decision./

A says that nursing home placement would be very difficult and sad.	The thought of institutionalization makes him cry.	
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I think I've covered most of the stuff I think about family and friends have been good they provide support.

A says he has social support from friends and family.	He has family and friends who know about the situation.	
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She was very friendly and engaged had a lot of friends she can't do that anymore so everybody understands we've been very active in church for a long time have a lot of friends there a lot who are going through the same thing I got your flyer from one of my friends at church anyhow were putting together what amounts to a support group within the Church in addition to what the Alzheimer's Association has they've been a good support we've appreciated their help /

A says his wife is not the social person she used to be. He has participated in a program at church developing support for others in their position and have also used the Alzheimer's association as a resource	As his wife has withdrawn socially he has engaged with others in his situation and sought resources for support,	His wife's personality has changed significantly from very social to isolated, he is seeking out more social connections and support.
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and so we've talked pretty honestly and openly about what's going on among ourselves and not just those with partners going through this, other friends that we have understand so we don't have to make a lot of pretense about what's going on so that's helpful/

A reports that being open with the diagnosis and situation has been helpful	With this support he doesn't feel the need to diminish the experience, he can honest.	
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What else well when I sit here and talk about it, it gets pretty emotional. On a day to day basis you just have to separate yourself from the emotional thing and keep prowling on keep going can't get bound up in everyone's emotional problems what we're going through too if I let it get me down every day I wouldn't be much help so we/

A says on a day-to-day basis he is able to separate himself from the emotional impact of his situation but now as he talks about it he is very sad.	The day-to-day struggle and routine helps separate him from the emotional reality.	If he thinks of his wife as whom she used to be he would be no help to her in the present situation.
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I guess it does sometimes get to me like everything else. I have to go over the separation barrier and treat it as a daily chore, go on with what has to be done and not, especially when she gets angry she never gets abusive but she does verbally attack me sometimes— “You don't care you don't pay me any attention,” just have to shrug that off not take it personally and there are other times when she'll say how much she loves you and how she couldn't get along without you and that kind of thing

A says that in order to continue he has to establish an emotional separation a barrier to protect himself from his wife's emotional ability and not take verbal attacks personally	To be effective he removes himself from being husband and lover and is caregiver with tasks to complete.	He has to become impersonal to continue.
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You just have to accept this isn't the same woman really that you've been living with all your life, that things have changed and that some days will be better than others hopefully some extended periods will be better /

A says that part of managing his wife's care is understanding that she isn't who she used to be and that some days will be better than other days.	He characterizes his wife as now someone else yet still feels commitment to their marriage and history.	Personhood and personality have changed and his wife's responses are unpredictable.
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She's on some antidepressant medication hopefully that will have some effect these things will take a couple weeks to a month before you know and then if one doesn't work you have to go back and start again and that's kind of frustrating but it, so we hopefully we found the right one I think if we could get the depression under control some of these other problems would be easier too a lot of the depression expresses itself in what she considers to be headaches and ailments of one sort or another so she always has a new ailment she wants attention for./

A concludes the interview with optimism that treatment of the depression would make a difference, he understands that changes in medication take weeks to show effect, he feels that many of his wife's symptoms would resolve.	Rational explanation for situation looks towards medication for relief.	Holds out hope for improvement with medication changes.	Has some hope that the emotional disturbance will improve.
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So you have to see it for what it is, not, not, get worn down with it, go on and do the best you can./

A says you have to keep perspective and do the best you can or else you will get worn down.	Keeping a rational perspective protects against becoming emotionally worn down.	He can't relate to his wife or treat her the way he used to.	What dementia is to him is a slow process of changing his wife and companion to someone barely recognizable and still be able to see her value.
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Interview 4 Structure

After 47 years of normal family life and retirement, the situation changed. A particular event marked the change. His wife found a very familiar environment foreign. A medical diagnosis of dementia changed the focus of their lives. His wife's emotional responses are at times more concerning than the dementia. He must be vigilant all the time because she is not safe without supervision; she is at times irrational and acts upon delusions. His wife's responses can be irrational. He must be responsive the entire time he is with his wife 24 hours a day. He manages his wife's medications for dementia, depression and physical problems and still she is never really well, and usually lacks interest. She used to enjoy life and have many interests. Now she is like a different person, focused on herself. His role has become parental, looking out for her health and safety. She is ambivalent towards his presence and enjoys visitors who give her a break from him. She must always be supervised. Ensuring her adequate nutrition has become a power struggle. He provides custodial care for house and wife. There is a delicate balance to the situation and support relationships; he feels like introducing more people would confuse his wife. He takes his wife to medical appointments weekly, the medical providers seem to take personal interest in their situation, but there isn't much that can be done. His wife thinks that real help would change her situation. There is more stigma to Alzheimer's dementia his wife was glad she doesn't have that. His wife's contradictory demands make her impossible to please. "Nursing home" has the symbolism of abandonment. His wife is frantic with her sense of being a burden. His sense of responsibility requires that he take on the work. His sense of responsibility requires that he take on the work. Loss of companionship and the sameness of day-to-day living are hardest for him. Their routines have become restricted to the custodial. Activities that used to be fun are more work and less fun. When his wife lacks energy or interest it is more difficult for him to get through the day. His days consist of a series of emotionally and physically demanding tasks that don't seem to make a difference to his wife's wellbeing. He finds some reassurance that his experience fits a known pattern. Institutionalizing represents a kind of abandonment. His wife has taken out long-term care insurance so if he decides on this course she has already made it easier. The thought of institutionalization makes him cry. He has family and friends who know about the situation—this gives him emotional support. As his wife has withdrawn socially he has engaged with others in his situation and sought resources for support, His wife's personality has changed significantly from very social to isolated, he is seeking out more social connections and support. With this support he doesn't feel the need to diminish the experience, he can honest. If he thinks of his wife as whom she used to be he would be no help to her in the present situation (can't get bound up in her emotional problems). He has to become impersonal to continue. Personhood and personality have changed and his wife's responses are unpredictable. Has some hope that the emotional disturbance will improve. What dementia is to him is a slow process of changing his wife and companion to someone barely recognizable and still be able to see her value.

After 47 years of marriage and normal family life, his wife became confused and experienced their home as foreign, not knowing where she was. He was scared and took her to the hospital where she was treated for delirium, but never quite returned to normal.

Shortly after that she was diagnosed with dementia and their lives changed. From that point on their lives became focused on his wife and her condition.

He takes his wife to medical appointments weekly, the medical providers seem to take personal interest in their situation, but there isn't much that can be done. He manages his wife's medications for dementia, depression and physical problems and still she is never really well. He knows her prognosis is poor; treatment at best slows down progression towards total incapacitation and death. He has become parental, looking out for her health and safety.

Her condition fluctuates, sometimes almost her normal self, but it is unpredictable and he can never relax. He never knows what she will say or how she will act or what she may want. She is irrational at times and acts upon delusions. She is unpredictable. She must always be supervised. He must be vigilant all the time because he can't trust her to be safe without supervision—she could leave the stove on or the water running or go for a walk and get lost. Her contradictory demands make her impossible to please and communication extremely difficult. Loss of companionship and the sameness of day to day living are hardest for him. They have less and less meaningful interaction. Their routines have become restricted to the custodial—eat this; we have to get you dressed.

When she sleeps or takes naps, which some days seems all the time, he walks around their big empty house thinking about the life that went on there, raising their children. He is lonely. His days consist of a series of emotionally and physically demanding tasks that don't seem to make a difference to his wife's well-being. When she lacks energy or interest it is more difficult for him to get through the day he has to manage her daily activities, make her get up, make her eat. Ensuring her adequate nutrition has become a power struggle, they will negotiate a meal then she refuses to eat it. But doesn't she need to eat? She has to eat something to keep her strength. He knows she can't help it but he can't stop thinking that really she can and is being contrary—resisting in order to assert a self, which is disappearing. There is a day-to-day drudgery of sameness in the completion of care giving tasks that seems to stretch time out, slow it down. He has become custodian for wife and home.

This is not the same woman who was generous with her time and compassion for the ten years she was a hospice volunteer, the woman with whom he raised their children. If he thinks of his wife as the woman she used to be he would be no help to her in the present situation, he has to become impersonal and immune to her emotional fluctuations to be efficient.

There is a delicate balance to the current situation and support relationships. They have a four-hour a week helper that his wife really gets along with. He wants more help but this woman can't work more hours and he is afraid to introduce new helpers, more people would confuse his wife, so he wants more help but fears her negative reaction. But when the helper is there he gets to leave the house, usually to go grocery shopping, but out of the house, free for a little while.

He has family and friends who know about the situation and will listen when he wants to talk about his emptiness and loss. As his wife has withdrawn socially he has engaged with others in his situation and sought dementia resources for education; with this support he doesn't feel the need to diminish the experience, he can be honest, sometimes

even laugh with other people taking care of someone with dementia. There's some reassurance that her experience fits a known pattern of dementia, he has read about it in literature from the Alzheimer's Association, she is demonstrating expected or at least common behaviors that he has read about.

She usually lacks interest in her surroundings or activities, is withdrawn and sleeps later in the mornings and takes frequent naps, self-isolating. Sometimes she can't organize her mind and body sufficiently and needs to be bathed and toileted. She used to enjoy life and have many interests. Now she is like a different person, focused on herself, complains of headaches, physical aches that migrate and change daily. Any pill seems to help. She is irritated when her husband is around and anxious when he isn't. She asks permission for almost anything she wants to do. But that isn't much, her husband does everything.

She enjoys visitors, her daughters, who give her a break from him. She thinks that real help would change her situation but he isn't getting it for her. She knows she has dementia; she is relieved it isn't Alzheimer's, that's just horrible, it would be worse. He can't see that "vascular dementia" is much different. She is frantic with her sense of being a burden, yet hounds him with repetitious complaints and demands. She thought he might want to divorce her, another time she asked to be dropped off at a nursing home. He should forget about her. Every once in a while she just wants to die.

Institutionalizing represents a kind of abandonment to impersonal strangers. His mother in law had been in a nursing home and his wife and her sister were always complaining about the care. It's funny that his wife had taken out long-term care insurance a few years ago so if he decides on that course she has already made it easier. Maybe she had felt her mind changing then? The thought of institutionalization makes him cry. Gradually he has become a full time caregiver, there was no conscious decision; as her abilities have declined his responsibilities have increased. He had no choice. He is proud of what he is doing for her, just very sad watching her become someone barely recognizable. Their retirement plans and imagined future is gone. His wife is gone. He is the custodian of her memory. He has no regrets.

Interview 5

Some questions I'll feel free to answer and other questions. Are you going to ask me questions? I'm going to talk I think a lot of what I'll tell you is probably more general I don't necessarily have to go into too much detail and /

B states he is setting limits with the interview	The information and situation is personal.	
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Yes, ah, I'm very unhappy with the field of psychiatry. This is my first, first real experience with psychiatry, ah, I really am very unhappy. I went to two psychiatrists a psychologist and a counselor just to find out what she had, I went to two neurologists, the last neurologist that I went to, we go every 6 months to the university hospital a neurology professor, we visit with him every 6 months, nice extremely nice I can't believe the time they spend with us. But to this very day I don't know I'm not sure they know what she has, they think she has front temporal lobe dementia, are you familiar with that?/

B reports he is unhappy with psychiatry and neurology due to their inability to identify an exact diagnosis for his wife's situation. At the same time he reports the individuals are caring and spend time with them.	B is looking for an exact diagnosis to explain his wife's illness. Neurologists, psychiatrists and psychologists although compassionate have been unable to provide a definitive diagnosis.	The situation is medically ambiguous which is frustrating.
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They think she has FTD. We go every 6 months to (a hospital) and they, the medications she's been on, haven't changed. And they never talk about improvement, never talk about improvement, the reason I got rid of I don't mean, "rid of", the reason we didn't go back to the first two psychiatrists they were very negative and I couldn't live that way/

B says that although his wife has been on medications she hasn't improved. He has changed practitioners because of the bleak prognosis they gave. He can't live with that negativity.	The situation hasn't improved with medications and medical providers haven't offered hope and he needs to feel some hope for improvement.	The medical diagnosis offers little in the way of treatment.
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So we're now with a nurse practitioner because her psychiatrist left so we stayed with her and so what I do I have to look to see if there's anything out there to help her so when the article came out in the paper about 4 weeks ago on Ritalin that it might help people with dementia so I went to see my NP and you know what she told me? That "I saw the article in the paper and expected you to come in," and that's what I did, and she's on Ritalin now about 4 weeks—that I suggested./

B feels he must be vigilant about possible help and bring it to the attention of the medical practitioners. One medication his wife is on now is due to his research and suggestion.	Medical providers are not actively hoping to cure his wife's dementia.	He remains vigilant suggesting possible treatments.
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But as far as being a caregiver is concerned.

Diagnosed 3 1/2 years ago. The biggest number 1 job is keeping her clean. Believe it or not, she's half continent. She became half continent. At the beginning she was incontinent completely, but we gave, the psychiatrist gave her medication for depression and she became half continent. She wears disposable briefs, but her bowel movements she does in the bathroom—saves me a lot of work, but the biggest job is keeping her clean. That's the big job./

B states that the most difficult task of care giving for his wife is keeping her clean. She is incontinent of urine, but he is grateful she has her BMs in the bathroom. He attributes this to medication manipulation by the psychiatrist.	Care giving is physically difficult, the most demanding part being keeping his wife clean and dry.	Incontinence is a significant problem.
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She wears disposable briefs, and also I got her, on top of that, waterproof briefs and I even put an extra pad in the briefs so she's well insulated that's the #1 job, giving her a bath not a bath, shower that's very trying for me, cleaning the sheets doing the laundry./

B elaborates on the process of keeping his wife dry and adds that showering is hard for him as well as laundry.	Incontinence care includes padding waterproof briefs changing wet pads, bathing or showering her as well as the laundry.	Physical care of the body, hygiene, incontinence are physically demanding.
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Food, I was hesitant on using them but the senior centers in Albuquerque probably are the best in the US. We have our lunch there 5 days a week very healthy very tasty quite filling nice variety and you're treated very nice the centers are excellent so we use that, so that saves me, so all we need at night is a light dinner which we eat at home we don't eat out that much because I don't care for restaurant food I don't know how healthy it is and /

B says they use the Senior Center as a resource, they eat there 5 days a week, which is a great help to him. He just needs to fix a light dinner at night. He is concerned about healthiness of the meals.	Meal planning and preparation is simplified by the senior centers where they go 5 days a week for lunch.	He is concerned about maintaining good nutrition, found resource for this.
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I also eat at my son's house; he invites us over. He's a schoolteacher./

B says sometimes they eat at their son's house.	A son helps out with meals.	Some family support.
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So laundry is a job, food is still a job, shopping, I don't like shopping anymore at the beginning when I started taking care of her I didn't mind shopping but now what I do I try to stock up on food so we don't have to go very often we go to Wal-Mart where we are treated very well there I don't know if they treat the elderly well or not but we get treated very well/

Laundry food and shopping are difficult, he used to enjoy shopping. He no longer does. When they shop, he shops in bulk at Wal-Mart where they are treated well.	Laundry, food preparation and shopping are all difficult. He shops in bulk and goes where they are treated well.	They go everywhere together he has no respite.
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Well you might laugh, we don't drink milk, I'm intolerant to dairy products so we usually get 6 gallons of soybean milk and we're on that and it seems to be working very well and I think it's extremely healthy that was recommended by our family doctor./

B reports they drink soymilk because he is lactose intolerant, he feels this is healthy	Another example of his health promotion activities.	He follows health recommendations.
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What we do is I take her out of the house 7 days a week. We're out 7 days a week, a minimum of 6 days at the Jewish Center, we use the gym a minimum of 6, sometimes its 7 days a week, the Jewish center has a real nice staff and an indoor track, we use and we walk the track a mile a day we can go for months but we're very tight on the 6 days a week, /

B states that he and his wife walk the track at a community center 6 days a week	He takes his wife out every day and six days a week they walk a mile on an indoor track. More health maintenance.	He and his wife are active daily, which includes regular walking on a track at a community center.	He manages her body.
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I've taken her to all the local basketball games, I have season tickets for 60 years whatever all the lobo football games all the lobo basketball games we're always socializing at Senior citizen centers it's good for her and is good for me./

B reports that they are active, go to basketball games, socialize at the senior centers	He believes socializing is good for both of them.	Socializing is good for them both.	He continues activities the way they used to.
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I am getting tired—we were supposed to be traveling, we have traveled extensively we were married for 37 years, I have 2 children from a first marriage, my first wife, she's deceased and we have a boy who's a school teacher from our second marriage./

B reports that they had planned to be traveling at this stage in their lives that they have in the past. He and his wife have been married 37 years it is his second marriage.	They had hoped to be traveling at this point in their lives. They have been married a long time and raised children together.	He is elderly had expected to be enjoying life and traveling but is unable due to the current set of circumstances.
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We took care of her mother. Her mother was a widow, for 20 years so we looked after her mother for 20 years even though we traveled we traveled every summer.

B says that they took care of his mother in law for 20 years, even though they traveled every summer.	Care giving is part of their lives; they cared for his wife's mother for the last 20 years of her life.	Their dream and expectation was to travel, which now they are unable to do.	They were able to travel as well as meet family obligations.
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For 30 years our minimal travel, minimal, was 6 weeks. We had an RV which we didn't like. Hard to drive. Hard to park. It was too large for camping areas, so we got ourselves a Volkswagen camper. It was the most wonderful thing we ever bought. Our family has been in 49 states. So we traveled. We expected to travel, then her brother got sick. We took care of her brother for 8 years and her mother. Her mother lived with us the last 2 years of her life. She died at the age of 94./

B says they were able to travel extensively this was important to them. They took care of his brother in law for 8 years and for his mother in law in their home the last 8 years of her life. She died age 94.	Traveling was an important part of their lives but still they cared for his wife's mother and brother when they got sick.	Current situation is against a background of family obligations—caring for sick family members, including his wife's mother.
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She got sick a short time after her mother passed away and we thought it was depression she was 70 years old when her mother passed away so she had her mother for 70 years we were very close to her./

B says shortly after his mother-in-law died, his wife became ill. They thought it was depression.	He traces his wife's illness to the death of his mother in law.	Can identify an event as beginning of changes and dementia.
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Um. Well the house is suffering a little bit I got to clean the house up the house is not as tidy as it should be what I'll eventually be looking for someone to come to the house maybe three times a week, give her a shower do some laundry which would help me out./

B reports that he has not been keeping up with housework, eventually he will find a home health aide to help with cleaning and showering.	He may need help with housework and showering his wife.	He prioritizes his wife's care leaving some responsibilities unmet.
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I take her to Jewish services every Friday night. I'm very active in the Congregation (X). She's a Catholic but she goes to services with me. She likes services because of the music and we bake bread there every Friday morning. Are you familiar with Challah? We bake it every Friday in fact tomorrow we'll be baking and as I tell everybody, they have two shifts we come for the 8 o'clock shift because it's easier for me to get her ready, and they all breathe a sigh of relief when I walk in because I'm the dishwasher. I tell the whole world, you know they have a mountain of dishes. I'm very well organized. They have a mountain of dishes. I tell the whole world I'm the highest educated, highest ranked dishwasher in the city. I have 45 credits above the Masters and I retired as a Lieutenant Colonel from the Air Force and I wash dishes. Everybody gets a kick out of that, yeah, but they love when I walk in. Then they don't have to wash the dishes the amount of dishes when they were changing dishwashers and they couldn't wash the dishes 'til they completed that, so all the dishes they had to wash, see I wash dishes as they come in. One day we couldn't wash, they took a picture of the mountain of dishes, so many dishes. Anyway, I thought that was funny—the rank and the education—and I end up a dishwasher and she helps wrap./

B says they also go to religious services, his wife likes the music he is active in the congregation, on Fridays when challah is baked he is the dishwasher. Relates he makes jokes about being the best-educated dishwasher—he has credits above his MA and retired a Lt. Col. from the AF. His wife helps wrap the challah.	Frequent involvement with a religious institution where they go for services as well as helping in the kitchen. He is proud of their service.	He is able to get a sense of appreciation from their community service. His previous life achievements help bolster his current situation. As an afterthought, she helps wrap.
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(Asks about my religion) She likes services. She grew up quite heavily Roman Catholic she used to go, but not heavily. She goes to Jewish services now. She likes the music./

B tells me his wife grew up Catholic but goes to Jewish services now because she likes the music.	He projects her emotional response—she is nonverbal except when repeating numbers.	
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She her speech is almost zero a and then some of the things that I'm concerned with what's going to happen, people want to know why I don't find a nice place for her to live, well we've been married 37 years. I brush her teeth, floss her teeth. I brush her hair, comb her hair. I massage her face at night and you know you sometimes feel if you turn that over to someone else, that's not going to happen that's what's keeping me, /

B states his wife barely speaks, he details the loving personal care he provides, reports they've been married 37 years and knows the kind of care he gives would not be done by anyone else, and this is what keeps him doing it.	No one knows his wife and her needs as well as he does.	Continues caring for his wife because he doesn't believe anyone else could do it with the detail that he does.	Commitment to his wife and suspicion of inadequate care motivates his current situation.
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And I am concerned about the future so I really have to —and I've been negligent about making arrangements for her for the future. As far as getting help is concerned, are you familiar with, I don't know if I'm up to date, are you familiar with what kind of help I would get from the government? I'd have to be destitute. They allow me to have one house and one car and no savings before they'll step in to help me. So all my wealth, everything has to be gone before I can get some help./

B states he hasn't made plans for future care, that this is something he should be doing, he is under the impression to get government assistance he would need to be destitute.	He worries about the future and thinks he hasn't planned well, he is unsure of available services.	Thinking about advanced planning, worried about finances.
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Fortunately I have good income. I have three incomes: teachers' retirement, which is excellent—teachers' salaries have always been low but retirement is excellent; then I get military retirement. It's not a full retirement. It's a reserve retirement, but it's still good and I'm almost maxed out on social security, so I have income. I don't know how long that would last./

B feels fortunate that he has a good income, but doesn't know how long it will last.	His three incomes he has currently might not last.	
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We're hoping for a breakthrough she's in good physical shape I think her blood pressure is good she takes all kinds of medication but I'm hoping she'll be physically strong enough to take any kind of medication that might help her. This is the reason why we're 6 days a week here./

B says they are hoping for a break-through, and that's why they exercise to keep her in good physical shape, so she will be able to tolerate the treatment.	He is keeping his wife's body strong so when there is a treatment breakthrough she will be ready.	He is looking forward to a cure or at least significant gains in treatment.	Remains hopeful and confident that his effort has value.
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I'm not happy with the situation. We had planned, we had talked about after retirement we had planned on doing further travel we haven't been any place in 3 1/2 years, I have friends, family they invite me to Florida, Connecticut, Massachusetts, they & we just & if she was continent we could travel, /

B is not happy with the situation, they were supposed to be traveling at this point in their lives and as long as his wife is incontinent, they can't.	Repeats again how they had been planning on traveling at this stage, the incontinence is the barrier.	Grieving for the loss of a projected future due to present circumstances and incontinence.
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It's real strange the neurologist at X, he's a real nice human being I asked him if there was anything we could do to keep her from going in her briefs, he told me what I could do, he wanted me to cut her medication in half and then he wanted to know the results. So he himself was experimenting with a medication to become continent, to help her to see what would help her, but it didn't work, if she was continent we'd be able to travel so not being continent its almost an impossibility. I sit her in the bathroom frequently and that does seem, does save her wetting her briefs and she has bowel movements./

B finds it strange that when asked about continence the neurologist (who is very nice) tried experimenting with medications but it didn't work. Incontinence is a barrier to traveling.	Medication adjustment is experimentation. Incontinence is a major problem and a barrier to traveling.	Medical care is experimental, sees no clear benefit.
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We traveled extensively for 30 years well you're from the East coast have you ever met anybody that took the freighter from north Sidney, Nova Scotia to new Foundland? We did, we drove our car onto the you have to make reservations it's an ocean going freighter, we stayed there for a week and then left Nova Scotia, it's a province of Canada and went back to Sidney. Seven days a week they allow, and they put on 30, 40 trailers every trip. They allow no cabs on the ship they have to pick the trailers up on the other end with cabs, it's a fascinating trip I've only met one other person that made that trip you have to make reservations, they fill up. Why that one ship is a lifeline of Newfoundland everything they produce they want to send to the mainland goes out on that ship. I tell you a funny story about the ship we landed I don't remember the port but when we drove back on the ship they washed the car and I said isn't that nice. New Brunswick and New Foundland island have the best potatoes in the world but they had a potato plague that they don't want to carry over to the mainland so they wash everything that comes on board the trucks and the cars that go on in New Foundland they wash top and bottom, we did that together and our son was with us and something on that particular trip we rented a car in Connecticut, we flew to Connecticut, we took the train. For fun we rented a car we had the car for three weeks and the rental shop was fit to be tied, we put 6000 miles on the car in three weeks. And he was very upset because he lost a lot of money on the rental they lose money with the mileage. I said you wanted me to pick up the car and drive to a hotel and stay at the conference for three weeks then drive back to the airport you wanted me to put ten miles on the car. We've done things we've been from New Foundland to Victoria, Have you taken the ferryboat from Seattle? Have you been to the San Juan Islands in Seattle Harbor? /

B talks animatedly about a trip on a freighter with their son. Reminisces about good times.	They had such good times traveling, which they are no longer able to do.	Traveling was a big part of their lives, now they keep active around the community.	Reminiscence gives context to his current experience and some comfort.
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We haven't traveled in probably 4–5 years we used to travel extensively, the only obligation I had each summer was I had a 2-week obligation with the reserves the National Guard so the rest of the summer we took off./

B talks again about inability to travel for the last 4–5 years.	Their entire summers were spent traveling.	Incontinence has resulted in loss of their favorite activity.
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The first real sign the first real sign that something was wrong, she came up to me and said that she couldn't manage the checkbook anymore, she couldn't. What I saw was she was having difficulty staying in the lane when she was driving. My son was driving with her one day with her in the car. One day when she was stopped by the police. Normally when you can't stay in the lines they think you're intoxicated, so they stopped her. We don't drink at all. So they stopped her to find out if she was intoxicated. So they stopped her, they said "We stopped you because you aren't staying in the lane." They didn't arrest her, they just let her go. She didn't make a fuss about it. She didn't get any citation, but yes, she did get stopped. And I noticed it also. I had to remind her get back in the lane and then she started to wet in her briefs and then I got her into disposable briefs. She was still able, she was able to copy, to write numbers, if I wrote 1–10 she could copy. If I wrote her name she could copy, but right now.../

B reports the first indication he had that something was wrong, his wife told him she could no longer manage the checkbook. Around this time he noticed her inability to drive straight, in fact when she was driving their son she was stopped with suspicion of DUI. Then the incontinence. She was still able to copy numbers if he wrote them down, but no longer.	The symptoms happened rapidly over the last 3 ½ years; after his wife told him she couldn't manage the checkbook, she drove as if intoxicated and then became incontinent and unable to copy numbers.	His wife has become functionally mute, incontinent of urine and dependent on him, over the last 3 ½ years.	His realization of his wife's difficulties was abrupt; he might have missed earlier signs.
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People, you know we have good days and bad days. A good day is when I open the car door with my remote and she can open up her door, she sits in, closes the door and puts on her seatbelt—those are the good days the bad days are when I have to tell her to close the door and tell her to put on her seat belt./

B reports they have good days and bad days; good days are when she can get in the car by herself and put her seatbelt on.	Day to day symptoms are variable, good days get his hopes up.	Good days are when she is less dependent on him.
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What was it yesterday or the day before, the other day she had a very good day, she counted to ten, I'll try to get her, (talks to wife), can you count to ten? 1 2 3 4 5 6 7 8 9 10 (wife counts with him to 4, then says 6, 5)/

B attempts to get his wife to count after him to demonstrate how she is on a good day.	The cognitive decline is so severe that even mimicking his counting gives him hope.	
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So, we have good days and bad days a good day is when she has no trouble taking off her underclothes when she takes off her undergarments and she'll, she has her slippers on she won't take off the left slipper, but she'll take off her right slipper and put it back on again./

B reports they have good days and bad days, good days his wife can take off her clothes.	He finds hope in minor changes in attentiveness.	
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She can't brush her teeth; I take very good care of my teeth. I take very good care of her teeth. I floss her teeth—she neglected her teeth in later life and maybe that had something to do with taking care of her mother, some kind of correlation not enough time or the patience, tired out but she neglected her teeth but I take good care of her teeth, I take good care of my teeth and so I take the same care of her teeth as I do of mine I really brush it thoroughly and I floss. I can't give her mouth wash, she'll swallow it. I gotta be careful about giving her tooth paste. Sometimes I can get her to rinse it out, sometimes I can't. I give her a small dose of toothpaste so if she swallows it there's no harm. But mouth wash, I can't, I use mouthwash in fact right now I have prescription mouthwash I get from my dentist, since I get my prescriptions free at the base. What um she doesn't comb her hair. She doesn't brush her hair. She doesn't wash herself at all./

B gives details of the personal care he provides noting that he does for her the way he does for himself, specifically brushing and flossing his wife's teeth and combing and brushing her hair.	Provides all grooming care the way he does for himself.	She is almost an extension of him as he maintains her hygiene with the fastidiousness of his own.
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I pick the clothes out and I try to keep, like this, whatever this is called, this works out perfect. She needs long sleeves on a day like this, but she doesn't need a coat, so this works out fine./

B reports he picks out her clothes appropriate to weather.	He dresses, feeds, toilets and grooms his wife with little participation from her.	Most of the time she is like a walking mannequin.
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I'll tell you something she does, you know she ties her own shoes and she ties them properly you, meaning, you know when you tie a shoe properly the shoelace is in the proper position a horizontal position not vertical. She ties her own shoes; I make a big deal out of it./

B reports that he is amazed his wife is able to tie her own shoes and in such a precise manner.	There is hope in the tying of a shoelace.	The ordinary tying of a shoelace becomes significant and symbolic of retained personhood.
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To this very day as I'm talking to you, I don't believe that there's any of her doctors, four psychiatrists, two neurologists, and a NP, I'm not too sure that they've correctly diagnosed what her illness is. Because she does, I don't know, here. "Want to shake hands?" (Holds his hand out to his wife.) She doesn't do it anymore. One psychiatrist said he was walking around the room, he said she was watching him walk around the room and when he put out his hand, she shook hands with him and he told me that that is not a sign of dementia. It might be more depression. He's the one who gave her medicine for depression and her bowel movements, medicine for, saved me an amazing amount of work./

B reports that the way his wife ties shoes and the way she will shake hands, although she doesn't right now make him suspicious about her diagnosis. A neurologist suggested that it was more likely depression.	Does not feel there is adequate medical explanation for his wife's condition.	Lives with the uncertainty of the situation.
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You're not old enough to remember the insane asylums. The 1930s there was no treatment for dementia. This was in Connecticut, New York—same thing. If a person suffered from dementia they were put in an institution the institutions were called insane asylums. Her condition she would be considered insane. And institutionalized, no medication, so for many, many years there was no research then somewhere along the line someone figured maybe we could help them. Fix brain cells. I remember the insane asylums as children we called them crazy houses. Now if you say the word insane or crazy maybe you could get arrested you can't say that anymore. So what I'm trying to say, for many, many years when they should have been working on research for the brain they just let it slip./

B reports that in the 1930s there were insane asylums, which is where his wife would have been. He feels in the interim some research should have resolved the situation.	Lack of treatment is because we are behind the times in brain research.	Social priorities don't value research into mental illness.
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I've known people that were in these institutions for over 50 years. Ah, the children in the 1930s that were handicapped, with lack of intelligence, ran the streets. Are you familiar with the law in Albuquerque? Mentally deficient, whatever you want to call them. The only ones the schools don't have to take are the blind students; they have their own school. You know the public schools have to take all the other students and some are one on one, aren't they? The only ones they don't have to take are the blind. When I was growing up there was no place for those students, you know where they were? Those students were out in the street and those who could attend were sent to a central school until they were 16 and they were turned loose, an ugly horrible school system. And I remember that.

What I was bringing up is really many, many years passed, before they did any research with the brain and now we are years behind the times. Look at what we've done with poliomyelitis— it's gone and when I was growing up, it was a deadly disease, but they did research and now it's gone. A couple months ago, first I heard in 50 years, someone in

Albuquerque— my son’s principal, got scarlet fever—have you heard that? Even today? I haven’t heard that word in 50 years, but when I was growing up it was common. Diphtheria is long gone, but they did research. Look at what they did with AIDS. It’s on the back burner now because they have methods of treating it, preventing it, whatever, but they’re 50 years, 100 years behind in research with the brain. I remember when they did nothing with the brain. No research with the brain and this is the result./

B states that advances have been made in other areas of medicine but brain research has been neglected and the result is not being able to diagnose or treat his wife.	The current situation, the uncertainty of diagnosis is a result of ignorance and irresponsibility.	
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Another thing that surprises me, and you being a nurse, I told my family doctor, I mean I looked we did have believe it or not I can still do it, I tried to get into the Mayo clinic in Tempe, Arizona, but they weren’t taking any new patients so I got on the waiting list at the Mayo clinic in Orlando or St. Petersburg in Florida, but we got on the waiting list and they gave us a date and time, and I talked to the doctors, I’ll leave for China this afternoon if I knew there was something to help her, so I listened to the doctors, and the doctors at X—this is what they told me and my family doctor told me, they knew it would be a difficult trip they said if the Mayo clinic really had something that would help, they would know about it. So they think by her going there it would just help them in their research. It would help them more then it would help her. No way in the world I would travel 2000 miles and they would put her on a placebo? So I cancelled. They have all the information if I want to go./

B says he was ready to go to the Mayo clinic; he would go to China if he thought he would find something to help his wife; he was told if they had anything effective there his doctors here would know about it, meaning that her going there would only help research and she might be given a placebo.	He would travel any distance to find real help but if there really was help that information would be available here. To him research means the possibility of being on a placebo. And really helping out the researchers, not his wife.	He has given up searching for a cure from the medical establishment.
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I’m discouraged. I’m encouraged by the X by my own family doctor, by my psychiatric office to not stop looking for help but that’s discouraging for me because that’s not my profession I mean the medical profession should be doing that. I walked in with the Ritalin, and the NP said I was waiting for you to come in because everything I read about mental health I think might help her—I’m in with the article, they get articles people bring them articles all the time./

B finds it discouraging to be encouraged by medical providers to look for help, for example the article on Ritalin, because he feels that’s their job not his.	He is discouraged about the lack of any good treatment and that he has to research treatment himself.	When his wife’s medical providers encourage his involvement in her care he feels more control over the situation.
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Has it helped? That's what the NP asked me, my family doctor has asked me, it's very hard when she has a good day immediately I think Ritalin's working if I have nothing to do at this particular time she is on 7 1/2 mg /day of Ritalin. The maximum she'll ever take is 10. She started on 5, we upped it to 7 1/2. In another few days we'll up it to 10. That's maximum, so there's a possibility we'll start her on 10. We have to be careful because it affects blood pressure, so I have to watch her blood pressure to make sure it doesn't go through the ceiling. But before I start her on 10, and of course I pray every day that it helps, but the question you ask, the question two doctors have asked, and I really don't know, I attribute her closing the door, putting on the seatbelt properly, putting on her undergarments, how she puts this on when she puts on her slacks zips up the fly, does the button herself. I'm thinking boy, does the Ritalin work just, so it's hard to tell. And I'm unhappy. I'm not happy./

B says he wants to believe it's the Ritalin working when he sees his wife able to put her seatbelt on and zip up her pants, but he is not sure. He is unhappy.	He can't be sure that the treatment he researched and providers put his wife on is doing any good. He is unhappy about the situation.	He is unhappy with the entire situation but sees no alternatives.
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I'm unhappy because of the, there are things we should be doing but we're not mainly, travel of course if she was well I wouldn't have 100% of the burden and at my age, 85, it's not going to get any better. She's 75. Do you have any questions? /

B reports he is unhappy with the situation because he wanted to be traveling at this point in their lives, and at 85 years old he has 100% of the burden. His wife is 75.	He is unhappy with the situation, at his age responsible for 100% of the burden; he feels things will not get better.	He is ageing, slowing down feeling the loss of the expected retirement life while he props up his wife's existence.
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[Are you done?]

Yes, and you can always call me. And how do you know Josh? I'll tell you a funny story about the walking. People play basketball and volleyball and I've met people at the supermarket at Wal-Mart[®] in the doctor's office I don't know them but you know what they tell me? They say aren't you the couple who's always walking around the track at the JCC there are many people who know us because they look up there, we're here 6 days a week,

B ends interview by relating how people in random places who play volleyball or basketball at the gym will tell them they see him and his wife walking at the gym. He seems proud of this.	He is proud of his care giving.	Ultimately he is proud of what he is doing for his wife.
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Interview 5 Structure

The information and situation is personal. The situation is medically ambiguous which is frustrating. The medical diagnosis offers little in the way of treatment. He remains vigilant suggesting possible treatments. Incontinence is a significant problem. Physical care of the body, hygiene, incontinence is physically demanding. He is concerned about maintaining good nutrition, found resource for this.

He has some family support from their son. They go everywhere together he has no respite. He follows health recommendations. He manages her body. He continues activities the way they used to. He is elderly had expected to be enjoying life and traveling but is unable due to the current set of circumstances. They were able to travel as well as meet family obligations. Current situation is against a background of family obligations—caring for sick family members, including his wife’s mother. Can identify an event as beginning of changes and dementia. He prioritizes his wife’s care leaving some responsibilities unmet. He is able to get a sense of appreciation from their community service. His previous life achievements help bolster his current situation. As an afterthought, she helps wrap. He projects her emotional response—she is nonverbal except when repeating numbers. Commitment to his wife and suspicion of inadequate care motivates his current situation. Thinking about advanced planning, worried about finances. His three incomes he has currently might not last. Remains hopeful and confident that his effort has value. Grieving for the loss of a projected future due to present circumstances and incontinence. Medical care is experimental, sees no clear benefit. Reminiscence gives context to his current experience and some comfort. Incontinence has resulted in loss of their favorite activity. His realization of his wife’s difficulties was abrupt; he might have missed earlier signs. Good days are when she is less dependent on him. The cognitive decline is so severe that even mimicking his counting gives him hope. He finds hope in minor changes in attentiveness. She is almost an extension of him as he maintains her hygiene with the fastidiousness of his own. Most of the time she is like a walking mannequin. The ordinary tying of a shoelace becomes significant and symbolic of retained personhood. Lives with the uncertainty of the situation. Social priorities don’t value research into mental illness or dementia. The current situation, the uncertainty of diagnosis is a result of ignorance and irresponsibility. He has given up searching for a cure from the medical establishment. When his wife’s medical providers encourage his involvement in her care he feels more control over the situation. He is unhappy with the entire situation but sees no alternatives. He is ageing, slowing down feeling the loss of the expected retirement life while he props up his wife’s existence. Ultimately he is proud of what he is doing for his wife.

Beginning with his mother-in-law’s death, his wife started declining cognitively. At first turning over the checkbook to him, then no longer able to drive, and now is incontinent and doesn’t speak or respond with a social smile. She is dependent on him for all ADLs although she walks. He holds her hand and she follows. The situation is medically ambiguous which is frustrating for him because the diagnosis offers little in the way of treatment and the prognosis is poor which he has a hard time accepting. He feels dementia has been marginalized by other social and medical priorities because of ignorance and responsibility. He has given up searching for a cure from the medical establishment. He sees

medical care as experimental, no clear benefit from medications. When his wife's medical providers encourage his involvement in her care he feels more control over the situation.

He is also ageing, slowing down feeling the loss of the expected retirement life while he props up his wife's existence. He is elderly had expected to be enjoying life and traveling but is unable due to the current set of circumstances. He grieves for the loss of a projected future and his wife's companionship. He finds it hard and lonely dealing with someone who doesn't communicate. His life has become focused on her.

Ultimately he is proud of what he is doing for his wife.

Incontinence is a significant problem as well as general physical care of his wife's body, nutrition and hygiene, which is physically demanding especially for a man his age. In addition he is responsible for the associated housework and laundry. He has some family support from their son. He follows health recommendations from medical professionals with whom they have routine appointments.

He continues activities the way they used to going everywhere together without respite.

He socializes at senior centers, community centers, with her at his side watching without affect. He reminisces about their life and travels together before the dementia and incontinence, (which to him is the major barrier from traveling). This reminiscence gives context and comfort to his current situation.

He projects his wife's emotional responses—she is non-verbal except when repeating numbers. She has almost disappeared in his story except in terms of tasks related to her care. He finds hope in minor changes in her attentiveness. She is almost an extension of him as he maintains her hygiene with the fastidiousness of his own—flosses her teeth and massaging her face daily. Most of the time she is like a walking mannequin that he grooms and ambulates. The ordinary tying of a shoelace becomes significant and symbolic of retained personhood—there is someone there. Good days are when she is less dependent on him—not waiting for him to put on her seatbelt.

Commitment to his wife and suspicion of inadequate institutional care motivate his current situation.

He remains hopeful and confident that his effort has value to his wife He is thinking about advanced planning but has not researched options. Lives with the uncertainty of the situation He is unhappy with the entire situation but sees no alternatives.

Interview 6

Okay it all started back in 05, 2005, wife Lois was diagnosed with iron deficiency anemia and lost a ton of weight. She went from about 160, which had been her long-term average weight, and she bottomed out at about 114 and we thought we had lost her at that time, we did see Dr. Vigil, the oncologist, who was my oncologist. And he brought her blood back to normal within oh about a year or so but I always look at that incident as the start of the whole thing, and I don't know if there's any correlation between Fe def anemia and dementia, I just don't know I'm suspicious because that happened to her./

Mr. C reports that he believes his wife's dementia began in 2005 when she had iron deficiency anemia. She had lost a lot of weight and the family thought she was dying. His oncologist treated this, within a year her blood work was normal, but C believes it was the event that started the whole process.	There was a specific time and set of circumstances that seemed to begin the current state of affairs.	
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With respect to the care giving aspect I have, we have 2 children living here in town one is J (son) who works with me here and the other one is P (daughter) who is a retired school principal here out of APS, She took retirement about two years ago and then we have a part time caregiver come in 4 days a week, 4 hours a day, to relieve us, to give us time to get our own stuff done.

C reports that in addition to him, his son who works at the accounting office with him and his daughter who retired from a job as school principal help with his wife's care.	Their children help with care giving and they have employed a part time helper.	3 family members and a hired part time helper provide 24-hour coverage.
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I myself stay home with her in the morning I used to get her up and shower her and clean her and make some breakfast and whatever, and we've gone through that cycle and she is as of right now wheel chair ridden she has a serious arthritis problem in addition to the Alzheimer's.

C reports his tasks include getting his wife up in the AM, providing grooming and bathing care then making her breakfast. In addition to dementia his wife is wheelchair bound related to arthritis.	His experience has involved cycles and stages. His wife is in a wheelchair secondary to arthritis.	Co morbidities add to the physical/ lifting aspect of care as the disease progresses.
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I stay home until about noon one o'clock or so and then I come here to the office for the rest of the day. Son J comes now at noon time and helps her up and to the bathroom and

whatever and P comes over and they get her showered and whatever else so I'm lucky if I had to do it myself there's no way I could do it so son J is probably the lead caregiver beside myself.

In the afternoon C reports his son and daughter take over care and he goes in to the office. C states he feels lucky, without his children's help he would be unable to continue care giving.	If he didn't have his children's help he would be unable to provide the care himself.	The care is highly organized the same routine from day to day with specific times and tasks for each of them. One person could not do it alone.
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I'm lucky to have J with me, happens he lives right next door we fixed it up so he bought the house next door and its very convenient, daughter P lives a block away so it takes the three of us to handle the situation./

C states his son lives next door, this was something they arranged for care giving purposes, and his daughter lives up the block. C says it takes the three of them to manage his wife's illness.	His wife's care is the focus of his and two of his children's lives.	The 2 adult children live within a block of their parents in order to provide more convenient care giving.	His wife's care is the focus of his, his son's and daughter's lives right now.
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We went through the typical stages of Alzheimer's we went through the embattlement that I guess there's four or five things in Alzheimer's, things that you go through. We've been through the violence, all through that stuff./

C relates his wife has gone through typical stages including embattlement and violence.	His wife went through typical stages of disease and is now calm.	
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As of right now she's in pretty good shape, sleeps a lot and we give her medication in the morning and the evening and she sleeps from about 9 o'clock at night until noon the next day. She sleeps well. She eats well. Doesn't communicate at all. Doesn't recognize any of us, but every now and then you see a spurt of the old L. She was a feisty one. She was a party girl. She liked a good party and she still does./

C reports his wife is in good shape now, relative to the previous embattlement and violence. She sleeps long hours, no longer recognizes any of them. Once in a while her previous feistiness comes through.	His wife sleeps 15 hours a day and eats well. Except for slight glimpses of her former self his wife does not recognize them and doesn't communicate. No behaviors making it difficult to clean and feed her.	Although his wife is non-communicative and doesn't recognize them he sees in her sparks of who she used to be.	They provide custodial care for his wife who is docile and no longer speaks. He holds onto memories of the way she was.
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Likes her kids around her. We have five children and the other three visit us sporadically. One in Denver comes down about once every 6 weeks. The one in Dallas every quarter and the other one's in Las Vegas. He comes maybe twice a year, that's it. So it's really up to the three of us locally to take care of her./

C says his wife likes the children around, in addition to the two participating in care giving they have three others who live out of town who visit every 6 weeks, quarterly and biannually respectively.	C moves around in time as he tells his story. There is a range of involvement among the five children, from daily to twice a year.	There are different levels of family involvement; the in-town kids provide daily care; the out-of-towners sporadic.
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It's a drain as you can imagine, but as I have taught our kids, you play the cards you're dealt, and if we were dealt Alzheimer's and dementia, we're going to make the most of it./

C reports that what they are doing is a drain but he has taught his children that you live up to your responsibilities.	He knows their care giving is draining but it is their duty and responsibility.	There is no moral alternative to the situation; he is doing the right thing.
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And wherever we go, she goes, is it embarrassing some days? Yeah on the other hand I have little business cards printed up that I do give out that indicate she does have Alzheimer's that we give to people we have contact with so if she says anything out of line at least they'll understand./

C reports that they have had embarrassing moments in the past. They printed up explanatory cards to hand out when that happened.	At times his wife's behavior was embarrassing to them; his response was to make up cards he could hand out explaining the situation.	When his wife was not herself he communicated her situation via calling cards.
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It's really funny different reactions according to the age you give it to, the younger generation really don't know what it is—unfamiliar with how the disease operates, the older generation very considerate /

C reports he has had different reactions to these cards—older people are more understanding.	Older people were more understanding and considerate of the situation.	He reaches out via cards for validation from his peers.
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Because what we found and dealing with the oncologist, he happened to be my cancer specialist, the first thing we noticed that went and as he commented on, the inhibitions in the brain and so we took her to a doctor's office, as one doctor at the U said, "she has very colorful language,"—nice guy with the gerontology department, yeah no they don't have any inhibitions at all makes no difference if you're in a restaurant in the car or where you are so it was kind of a shocker to us as caregivers, we learned, you know you read a lot try and get familiar with the disease get to understand the various stages./

C reports that one of the expressions of Alzheimer's is disinhibition—colorful language randomly, which prompted the cards.	Early on his wife's lack of inhibition, just speaking out, swearing shocked them, which prompted their education about the situation.	The wife's disinhibition can get embarrassing and can offend others, he explains so they will understand.	His wife has become "they" as he followed stages of Alzheimer's.
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Some people come down with the disease and are gone in a very short period of time we're going on our 8th or 9th year now and the physical aspect of it she could outlive us all she is just tougher than nails and as long as they got a clean bed to sleep in clean clothes to wear and eat well and sleep well and all of her vitals are perfect she could go on or on the other hand they could go tomorrow. You just don't know./

C says that from what he knows about the disease, it is unpredictable. They have been caring for his wife for 8 or 9 years and he believes as long as she is well taken care of she could out live them all or die tomorrow.	They have been care giving for 8 or 9 years and the future is unpredictable.	He deals with the uncertainty of the situation on a daily basis.
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. . .the three of us; of course, I'm the primary care giver as the husband. We've been married 55 years now. You never think that's gonna happen to you, but it does, and those are the cards you're dealt and you deal with it and we refuse to put her in an institution. That's the way we were brought up. You take care of your elders. Our five kids all know the rules and they understand it. They're bending over backwards to help./

C reports that he and his two children bear the brunt of the work. He says he has been married 55 years, that he had not expected this state of affairs but that's what happened and he was brought up to take care of elders, institutionalizing is like abandonment. His children know these rules.	Life is a game of chance. Dealing with it doesn't include institutionalizing your elders.	In the context of a 55-year marriage and 5 children this is his responsibility and correct course of action.	Institutionalizing his wife has bad connotations, representing abandonment vs. his responsibility to care.
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I'm pushing 79 in 2 months. I come here. This is our accounting and tax practice, but I do that as an outlet for me. It's my life, it's my career. I love it. It gets me away from those pressures of care giving./

C says he is almost 79 and continues to work at his accounting practice, which he loves, and it offers him respite from care giving.	He is an elder, continuing to work helps with the pressures of care giving.	The care giving is in the context of his ageing, which he balances, with the respite of lifelong passion for work.
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But she's totally incontinent I learned to do a lot of laundry and a lot of household chores, that's what I do in the morning when she sleeps I try to get the house tidied up and do the laundry and that kind of thing, /

C reports his wife is incontinent requiring him to learn laundry and other chores, which he does in the morning.	A major pressure of care giving is his wife's incontinence, which has required him doing lots of laundry. Now that his wife sleeps until noon he is able to keep up with household chores and laundry in the mornings.	Incontinence has a dramatic impact on care giving.	Care giving provides a routine set of tasks to pass the time.
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So we all have a role in what we're doing I'll take care of the morning get the housework done caregiver comes in the afternoon and then in the evening we get together we have dinner with her it's the four of us and we get her in the wheelchair to the table and she participates with us right there, /

C reports they each have their role tasks, but in the evening they sit down to dinner together.	They tag team throughout the day each with their specific jobs.	The family involvement keeps his children engaged in a semblance of maintaining his wife's previous routines.
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And then the other two leave and then I spend time with her in the evening before she goes to bed. I'll sit with her, she wants someone to sit with her; she's at that stage, I'll do that for a couple hours 'til 9, then the two kids come back, and we all get her ready for bed. That's kind of our schedule pretty much for the last 8-9 years./

C says that after dinner his children leave and he and his wife spend time alone. He says that wanting to have someone sit with her is a stage. After a couple hours his children come back and get his wife ready for bed. They have been doing this for the last 8 or 9 years.	He sits with his wife for a couple hours in the evening but then the two children come and they all get her ready for bed.	For 9 years the focus of their lives has been care giving.
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I believe we're doing great. That's my personal belief. I've also told our kids, let's keep a sense of humor no matter how bad it gets. Let's keep a sense of humor. Some of the things that she says and does, you just gotta laugh your tail off. It is really funny and you don't do that in a demeaning way./

C believes they are doing a great job of care giving. He is boosted by a sense of humor, which he reinforces to his children.	He feels they are doing a great job, which he attributes to maintaining a sense of humor. He recalls his wife has had some funny episodes.	Finding humor is important to managing the situation, which is physically and emotionally difficult.	The situation keeps getting harder as the dementia worsens.
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For example she talks a lot at night and we give her Trazadone to help her sleep and she sleeps like a log but the Alzheimer's dementia thing is very similar to Parkinson's Disease,

they treat it the same way with the same drugs, and she's in the other bedroom at night, and all of a sudden at 2 in the morning she's busting out laughing her tail off, a good old belly laugh like she used to have, and I can tell she's at some party. She was a party girl and it's really funny. I'll wake up because I hear the noise and she'll be laughing her tail off. I'd like to know what party she's at. I'll go check her, make sure she's okay, but it's funny. It really is funny. And some of the quips she says. She seems to be more alert the first hours when she wakes up and some of the things she says are funnier than a crutch, I mean it's the good old days and with her language added to it, you just gotta laugh and I think that's good. I think no matter how hard it gets lets everybody keep a sense of humor, including her and she does. She was always a good humored gal and I don't want her to lose that. And she gave that attribute to the kids. The kids are all that way. So we're having a good time taking care of her, really./

C reports that every once in a while his wife will wake up in the middle of the night laughing. This delights him and reminds him of the way she was in her younger days. She always had a good sense of humor and imparted this to her children. If they all maintain a sense of humor they will manage. They are having fun.	His wife used to talk a lot at night so they gave her a medication also used in PD treatment to help her sleep but still at times he would hear her laughing alone in her room which would make him feel good, that even she is keeping a sense of humor. He remembers the fun.	There are times when his wife seems to be enjoying herself in a different time and circumstance in the good old days, which is reassuring to him.	Although his wife no longer talks he recalls humorous things she has said in the course of the dementia. Memories of who she was fuel his perseverance.
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Is it work? You bet, 24/7, yeah it is. But we are bound and determined to keep her home, make her as comfortable as we can, and give her the medication, take her to the doctor, do whatever. Ironically, today she had Coumadin and we went to the clinic at the university. We go once a month get the INR rate, but she's willing—no fight, no nothing. She just, everybody takes care of her and she's good that way./

C reinforces that care giving is lots of work. He repeats that they are determined to keep his wife home and comfortable. He notes that she went agreeable for her blood work today.	It is round the clock work but they will keep her home.	Round the clock custodial care is easier with her passivity.
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We had an incident when she broke one of her front teeth off and of course at her age, she's 75; 76 they don't replace those. There were pretty tense moments, but even then for what she went through, she did really well. She toughened it up and she was in good shape./

C notes that when his wife chipped her front tooth they were worried at her reaction but she remained calm.	His wife's responses are unpredictable.	The dementia has progressed to the point she does not react strongly anymore, making care easier.
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We take her to the cabin we have a cabin on the Canadian border we're from Minnesota, and we're taking her up in two months for the opening weekend of fishing. We fly from here to Minneapolis. As of late the last couple years, it has been great. There was a period there, she seems to have gotten quieter, /

C reports that the family is from Minnesota and they continue their routine of visiting, taking his wife with them, lately she does well.	They have maintained their routines, including vacations to their cabin, which has recently become easier due to her becoming quieter (which he doesn't verbalize as decline).	They assist her through the motions of their lives together in the past.	They care for the spirit of the person she used to be.
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But there was a period in there she was very vocal, if we got her in the plane John sits on one side I sit on the other we keep her between us but it's a project getting through TSA at the airport I can tell you some experiences there, and that's why I had the card made up./

C says now his wife is calm, but traveling with her when she was vocal was difficult. They had to hem her in on the plane. It was traveling incidents that originally inspired C to write up the cards.	He recalls previous difficulties traveling by air that prompted his carrying explanatory cards.	There are outsiders to the situation that they have had to insulate her from.
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Essentially the TSA folks are totally uninformed about Alzheimer's, dementia patients they don't know how to treat them and the first incidence was pretty bad this was 3-4 years ago when she was in the violent stage and they didn't know how to deal with it so I had these cards printed up for the next trip and I handed them out and said here pass these around so I watched as they got spread around and they were alerted. The first time I can relate was when they started the pat down. And you don't take L and start patting her chest down. And a little young girl started doing that, patting her chest and bam! She caught one right in the face. Knocked her and then the gal goes back and patting her chest and bam! Does it again really hard and the guy behind me in line kind of laughs and I said, "You know what I'm dealing with." I said, "Better call the supervisor."/

C says that 3 or 4 years ago they were traveling through the security checkpoint at a more violent stage of his wife's disease. When pat down she struck out at the security agent a young woman who continued the pat down and got struck again. It was this incident that prompted the cards. The man behind C in line laughed with C understanding what he was going through. C called for a supervisor.	The previous incident involved ignorance regarding the nature of dementia.	He expresses pride in his wife's resistance to her situation and the outside world and feels validated when his peers recognize his situation.
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And I talked to the TSA folks here and in Minneapolis before we fly and just alerted them and said, “Hey you guys have to learn how to deal with these people and I’m not asking you to forgo any of this security stuff but with Alzheimer patients you better be careful with what you're doing or somebody is going to get hit.”/

C says that now before they fly he contacts TSA to let them know the situation, he told TSA they need to become educated.	Many people are ignorant regarding Alzheimer’s.	
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Because I’ve seen incidents when you take a gal at 100 pounds that’s got Alzheimer’s and she can deck a 200-pound guy—I mean their adrenaline gets strong and they've got to understand that when you've got Alzheimer’s and you're at that stage where the violence kicks in I’ve seen that in my house she went through the violent stage knocked over end tables with lamps on them. She could break up the joint, but after about a year and a half that quieted down, so we don't see that anymore, Yes it’s kind of a shock how violent they get and how strong they are./

C has experience; he has seen Alzheimer’s patients get violent and powerful from their adrenaline. His wife went through a stage of violent behavior for 1 year and a half.	People need to know, more about Alzheimer’s, particularly those in positions of authority,	There have been significant behavioral challenges that have isolated them from mainstream living.
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So on the airplane we put her between us and early on when the plane didn’t take off right away she let them know, “let’s get this buggy going” all nice and loud so everybody in the cabin heard. Now she's quiet and, but she was pretty outspoken initially. It’s pretty hard getting into the cabin and into a seat when you’re in a wheelchair— on top of everything else./

C notes there were situations where even though they got her on board and were sitting on either side of her she would get vocal.	His wife’s lack of appropriate social restraint was sometimes embarrassing.	They stick together and buffer his wife in order to keep long-term routines in place. They have overcome challenges.
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But again, I notice the adults kind of understand. They have some experience with this stuff, but the younger set just doesn't have a clue what could happen. It was our education we learned that, It happened at Sadie's restaurant one night the poor gal was waiting on us doing something and it wasn't right whatever it was and boy she let her know about it in no uncertain terms, and that's when I started carrying the card with me because if the younger people don't understand your gonna get some reactions is what's gonna happen. /

<p>C repeats that younger people have less understanding of the situation. They were at a local restaurant one night when the waitress did something that annoyed his wife and had no understanding of the situation. This was part of their family's education and they responded by providing cards.</p>	<p>The printed explanatory cards are one way of bridging the ignorance gap.</p>	<p>The background is ignorance regarding dementia particularly in younger people.</p>
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But through it all from a caregivers standpoint we're riding high right now I've got the two kids with me We've got the routine, a schedule of assigned tasks, what we're supposed to do—we take excellent care of her get her to the doctor's appointments, I take her medication—she's on a lot of medications many different drugs and I take care of that aspect of it, that's a problem getting scripts renewed, as of right now we can keep this thing going for a long time as long as everyone keeps calm and understands what we're dealing with and keeps a sense of humor about this whole thing we'll be okay. How long it will last I have no idea./

<p>C feels that at the moment the situation is under control and can keep going indefinitely as long as everyone keeps calm, keeps in mind their purpose and maintains a sense of humor.</p>	<p>Right now his wife doesn't communicate or resist care, which makes their routine easier; he doesn't know how long this will last.</p>	<p>The current organized routine of assigned care giving responsibilities can continue indefinitely as long as there's no deviation from the course. The situation is tentative and fragile.</p>
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Her mother was like that in that condition for about 15 years. She didn't recognize me for the last 14 of them and I don't think she recognized her own daughter. And I happen to believe those things have something to do with it, your family background, and so forth and we're only on year 8 or 9, Keep cool keep a sense of humor, do what you're supposed to do and everything is working out fine./

<p>C notes that his mother in law lived with dementia for 15 years, 14 of which she didn't recognize him or his wife. He imagines this might be predictive of his wife's situation, meaning they have another 6 or 7 years so it is important to maintain the sense of humor and tasks.</p>	<p>His mother in law lived with dementia for 15 years so they may have a long time ahead of them, it is important to keep a sense of humor.</p>	<p>It may go on for another 6 or seven years so humor is very important.</p>
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I am, I have no complaint. Like I say, you deal with the cards your dealt and I happen to have a broad perspective about that I wouldn't put her in a home unless I absolutely had to and I don't see that happening. My grandpa lived with the family when I was a little

tyke and I remember that. I remember that so I think either you're in align with that philosophy—that you take care of your elders and you grew up with that and you abide by that and there are those who don't, who walk away that would be the last thing like I say./

C reinforces that he has no complaints; repeats that you play the cards you're dealt. He feels this outlook is a character trait—that you learn you must care for your elders. Walking away from his responsibility would be the last thing he does.	What he and his children do as caregivers is part of a greater philosophy of caring for each other as part of life responsibility.	A "home" represents abandonment to strangers.
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The care giving aspect is busy; dealing with someone who doesn't communicate is hard in the first place. We'll ask her, do you have to go to the bathroom? And I would say probably 50% you get a response she doesn't recognize anybody by name, although every now and then she'll have a spurt.

C reports that the fact his wife is minimally communicative makes it difficult to anticipate her needs. For the most part she doesn't recognize her.	Caring for the body is hard when the person can't assist caregivers.	There is additional struggle with care giving to a person who can give little or no feedback. No recognition.	The person for whom they are performing this service may be unaware of their effort.
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She knows that daughter J lives around the corner, and her and J have always been very close, and every now and then she'll pop up with the word J. (Son) is single and he is a dream taking care of her and every now and then she'll call his name, but very few and far between—sporadic./

C says that his wife is still aware that her daughter lives close by and sporadically may say her son's name.	He recollects his wife's diminishing awareness.	Small indications of appreciation or awareness are amplified.
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Occasionally, occasionally, for example I'll have some piano DVDs on because I used to be a piano player years ago and she'll say that's L—so there's some recollection of that, but that's so rare now. It got progressively worse as time went on. It's rare that she recognizes me./

C says that it is extremely rare that she recognizes him, but she has recognized him on a DVD of his piano playing.	She rarely recognizes him, and then it is in the context of the past.	His wife shows very rare response to her surroundings.	Her self/personhood is almost completely gone.
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If she doesn't like something she'll tell you no doubt about that—between us we always make dinner I try to make things she used to make years ago. I think there's some correlation between what she used to make and what she likes to eat. So I'll do that, what she

used to make once or twice a week I'll make what she used to like, if the kids make something she doesn't like she'll let you know she just won't eat it, so we've learned we'll give her the stuff she likes and get on with it./

C reports that even as non-communicative as his wife is she will let them know if she doesn't like something. He states that he chooses menus according what she used to make, he thinks she must have made it because she liked it. If she doesn't like it she won't eat it.	Eating and food choice is a point of contention even with diminished awareness of surroundings.	Contradicts himself and indicates examples of his wife asserting her personality. She does this with refusal of certain foods.
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Yeah she's got that spunk in her where if she doesn't like something boy she'll let you know like that poor girl patting her down on her chest Lois was, you can say its puritanical but she always liked a good party but she didn't mess with the guys and she didn't like anyone to touch her./

C recalls his wife's spunk with the TSA agent— recalls that even though his wife enjoyed a good party she didn't mess with the guys.	Her resistance to foods she doesn't like reminds him her spirited approach to life.	He is reminded daily of happier times and his wife's spirited responses to things she didn't like.
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And she'll let you know about that real quick as the TSA folk found out so I guess some of the people understand it some don't so you've got to educate them as you go along. I've got a book I got early on, to me I think that's an excellent book and it goes through some of the stuff we've been going through the title indicates it's an epidemic, the more you look around the more you see, yeah it's an epidemic, there's no question I never realized paid much attention until it hits home and boy you have a different outlook on it. And I think it's an epidemic; clearly there's no question about it./

C states the importance of being educated about the disease, states that he read a specific book early on that refers to Alzheimer's as an epidemic, believes it is an epidemic.	This reminds him of how quickly his wife responded to the TSA people when they touched her, which reminds him of a book he read that helped him understand his wife's behaviors which reminds him that the book characterized Alzheimer's as an epidemic and he certainly agrees with that.	More people understand the nature of dementia, which is important since it is an epidemic. More people will be going through what he is now.	There is comfort in knowing he is not alone. Educating others adds to this.
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But the caregiver aspect to it—I'm lucky. How long we can keep that up I think its indefinite as long as she has some acknowledgement—she knows she has a clean bed to sleep in clothes to wear, the kids dress her. Yes, I think underneath it all she understands it./

C reports that as far as care giving, he is lucky. He knows his wife is aware of the good care she is receiving.	Where they are in the time line.	His wife acknowledges his efforts.	As long as his wife is aware of the care she is receiving he can continue indefinitely.
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She doesn't understand, she made a comment years ago "something's wrong with my head and I can't explain it." It was acknowledgement things weren't right. What it was, she didn't have a clue and neither did we. Until we got into it and we found out what it was, she could go indefinitely, really./

C reports that in some respect his wife was aware early on that something was wrong, but she was unable to say what. C believes the situation could continue for a long time.	Where they are in the time line.	Moves around in time—she knew something was wrong.
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The hardest part is realizing it's a 24/7 effort. Everybody realizes that—J, J, me, the rest of the kids, everybody— it's 24/7. That's the hardest part./

C says the care giving is a 24-hour process.	Experiencing the non-stop 24-7 nature of the experience, is the most difficult, it never stops.	Care giving is 24-hour vigilance and emotional and physical work.
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So I sleep with one eye open, we've had a couple incidents when she got up at night and tripped on the comforter getting out of bed and we ended up with a houseful of firemen and paramedics about 11 o'clock one night and she broke her collar bone, in two places is what she did. Ever since that time, we put a safety rail on the bed. I'm up at my age with a urinary problem. I'm about going to the bathroom 2–3 times a night, anyhow. So I just don't, I never get a good night's sleep but underneath it all if I hear the least bit of noise, I'm up out of bed like a shot because I know what happens—twice we had paramedics at the house because she fell so I learned./

C says even at night he has to be vigilant and gives as an example a fall when his wife broke her collarbone twice the paramedics were called. C reports a urinary problem that keeps him up at night anyway.	Non-stop 24-hour care includes nighttime vigilance, poor sleeping. He is an older man with an older man's prostate problem.	He is always on call.
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(Laughs.) Like I say, I'll wake up 2 in the morning and she'll be at a party laughing her tail off in there, Or she'll be madder than hell at someone, And it's the medication she's on the Trazadone, the Celexa, Namenda, and all that stuff. When you get elderly you gotta be careful on the drugs I mean it's easy in and easy out, you learn, I learn, that's how we do that, yeah I know every time I get up to go to the bathroom I check on her, I poke my head in the bedroom, check make sure she's snoring away, but so be it. I can sleep during the day. I'm doing okay./

C laughs recalling times he's found his wife laughing or angry at someone during the night. He considers the medication and reports that whenever he does get up at night he will check on his wife's condition.	Recalls a funny incident, declares his vigilance.	Remembering funny incidents helps hold the situation together for him.
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I'm proud that we can keep her at home and we're giving her the best life she can get. If we shipped her off to an institution we couldn't say that. Married 55 years./

C states that he is proud of the care they are giving his wife, he thinks that it is the best possible care, that it would not happen in an institution After 55 years of marriage.	Caring for his wife at home after 55 years of marriage is an achievement of which he is proud.	Uses "institution" "home" to describe the alternative.	Institutions and homes are abandonment to strangers.
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Matter of fact I married the girl next door, literally. I started out dating her older sister and that didn't sit well with Lois, so she and her sister haven't talked in a number of years. Married the girl next door. She was always a fun gal and she couldn't be more supportive of her husband and her kids, she just couldn't be' so I think we owe it to her. She's been dealt some bum curves and we're going to help her./

C reminisces about marrying the girl next door, who has been fun and very supportive of her family. C feels she is owed the care they are giving her.	There is reciprocity between his care giving and his wife's love and support for him and their children over the years.	He feels indebted to his wife for her years of companionship.
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I think, the kids and I have talked about it, it's 24/7 for all of us. What are we going to eat tonight? How is she doing this afternoon? And of course working with J (son), we communicate all the time and daughter J will call in 2-3 times a day, keep us alert, let us know what's going on./

C reinforces the 24-hour-a-day responsibility of care giving.	The details of care giving make up the context of their lives.	His children feel the way he does.
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I do have a cell phone I keep with me, I limit—but I don't give people the number too often because I keep it open if something happens I've gotta be there. So, done that for years. I bet outside the family there aren't five people who know my cell phone number. Because I think it's so important if the caregiver has a problem. I'm only 5 minutes, less than 5 minutes away, either J (son) or I can be there in several minutes, but that's us 24/7 you just can't get rid of it. There's no way./

C states that he has a cell phone primarily for communication regarding his wife's care; few people have the number because he wants to be available if needed. Even his office is only 5 minutes from the house. Repeats 24 hours a day.	He is on call when he isn't directly care giving and rarely more than 5 minutes away from his wife.	His whole life is about caring for his wife.
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What I try to do is get the kids to take 2 or 3 days, go watch baseball over in Phoenix, go to Minnesota for a football game, or do something to get a break. Old goat that I am I go fishing, /

C states he tries to get his kids to take time out for respite, he goes fishing	Encourages his kids to take short breaks and does this himself.	Respite time is important and keeps them "re-charged."
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But I tell you, some of the stuff—we have a cabin on the Canadian border, but just on a crazy whim—she's in a wheelchair so I said to the kids lets go for a boat ride, so we lift her in the wheelchair into the boat to go for a boat ride, daughter J has got a Speedo (jet ski?) and she's running next to us and Lois says "Is this as fast as this thing can go?" And I'm just busting up laughing because even though she's incapacitated in a wheelchair, she's a good old shoe got in the boat with us. And that was her comment, so./

C recalls a visit to their cabin when they got his wife on the boat in a wheelchair, daughter was cruising by on a jet ski and his wife wanted them to go faster.	Despite his wife's condition he easily recalls her good spirits and love of life.	His memories balance the current situation.
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When you bust your tail 24/7 and some people make a comment like that it's worth it trust me it's worth it, you just gotta laugh it's funny./

C states that when his wife says things like that it he feels their labors are worth it.	He feels comments like that keep him connected to the mission.	He keeps the current situation balanced by their lives together over time.
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It's hard at the cabin I don't know that she recognizes the wildlife we have up there the cabin sits 20 feet from the water we have birds and deer and bear, I'm not really sure she recognizes she's past that stage./

C states he is not sure his wife recognizes where she is when they are at the cabin.	Swings between memories of fun times and statements about how narrow his wife's awareness is currently.	He is uncertain of her current awareness of situations she has loved and has been very comfortable in before.
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We've been doing this for so long with the wheelchair, 7-8-9 years were going to the cabin in 6 weeks and if there's a recollection—she doesn't resist, 4 hour plane ride drive to the cabin stay in a motel yeah I think she enjoys every minute she wouldn't tell you that because she can't but she loved the cabin and she never wanted to go home she'd want to stay another

day I think that's there, all the kids are around her, she likes that so we'll keep doing it that's what we'll do I think there's some recollection to it./

C states that the length of time it takes to get to the cabin all the while in a wheelchair, and the way she used to want to stay longer rather than go home, makes him think that in fact she does feel some enjoyment there with her children around her.	Even so being in places she formerly enjoyed and now seems oblivious to is difficult for him. But he hopes and thinks she still has some awareness of the significance of the cabin and senses her husband and children around her.	It is important to hold out hope that there is some awareness.
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She was born in '36. L is 75, 76. She's 2 years behind me. My Mom went to 91. Her Mom went to early 90s. She will, probably. I wouldn't say that if she was in an institution./

C says that he thinks his wife will live into her 90s, which she would not do if in an institution.	Thinks again of possible longevity, which would be curtailed if she was in an institution.	"Institutions" are impersonal and don't provide good care.
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She liked it so well when the kids came in for the holidays and you can tell she recognizes something she doesn't know what it is but she recognizes something./

C states that when their kids were all together for the holidays he knows his wife recognized something.	She may not know her children are there but she can feel it.	His wife is emotionally responsive even if unable to recognize her children.
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But it's just something you live with I don't know if this is any help to you I have no particular secrets it's a family affair it's a project and were going to keep doing it as long as we're able I wished that it would be different. We all have traumatic experiences in our life this is ours one the kids are experiencing a little more but they're—and it's 24/7 and we take care of her like there's nothing wrong./

C states that it is just something you live with, do it as long as you're able and it is nonstop 24/7. They take care of her as if nothing was wrong.	This is part of life. Traumatic experience. Take it in stride.	Acknowledges the deeply distressing nature of the experience for all of them.
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I think that's how you gotta treat 'em. You gotta put some white lies in there once in a while—that's to be given. You don't mean anything bad by that, but that's the only thing. I don't know what your experience has been, but that's my story./

C says you have to tell some white lies once in a while.	Keep her insulated from the trauma?	Concerned that he has had to lie to his wife at times to keep her comfortable.
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At 79, you're just not as active as you used to be and I can't lift her. Presently she's weighing about 120 she's dead weight I can't do it, J can do it (daughter) can do it she's athletic all the kids are athletic.

C says he can't lift his wife, but both his children can.	He is physically not strong enough to lift his wife.	He is aging, which makes all physical effort harder.
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I can move her in and out of the wheelchair. J can do that. What we have her do is take baby steps. The caregiver, she's a Nebraska gal who could wrestle cattle. She could pick her up. The incontinence thing used to be sporadic. Now it's regular. That's come on over the last 2 years. But again, we've got the situation set up with the bed and all the other stuff and, typically, when the kids come at lunchtime to get her up and get her down stairs./

C says he can transfer his wife in and out of the wheelchair, as can his kids and the Nebraska gal caregiver. Reiterates that his wife is mostly incontinent.	Age related difficulty to care giving—decreased strength is one that his kids can help with as well as the part time hired caregiver.	The work is physically demanding.
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The boredom comes you do that stuff day in and day out everyone needs a break no matter who you are and the other kids know that well, the one in Denver drove out for a week, she spent the holiday week with us gave us a break. You just dedicate your whole life to it, I spend 3–4 hours here doing taxes I gotta stay active as much as I can because God help everyone if I go down./

C reports the day in day out work can lead to boredom. He says the out of town children are aware of this and come in to help. Their whole lives are dedicated to care giving. C reflects on what would happen if his own health was compromised.	There is boredom in the daily grind of tasks from which everyone needs a break.	The routine schedule gets boring and respite is important.
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I'm a cancer patient. I've had leukemia 12–13 years now. Was in a study at the cancer center; done with it last year. I've had prostate cancer, kidney cancer; I'm cancer prone. Besides leukemia, boy, I've gotta take care of myself so I can take care of her. It goes both ways here./

C reflects on his state of health notes he has had prostate and kidney cancer as well as leukemia. He says he has to take care of his own health in order to take care of his wife.	He is fragile with illnesses of his own which make it especially important for him to maintain his own health to continue his care giving.	He is a 79-year-old man with a history of cancer, with an awareness that his wife's ongoing care requires his health.	Apologetic about needing respite—rationalizing that he has had cancer, needs to take care of himself in order to take care of her.
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So we're getting along fine. So I'm cautious about my health and the kids' health. Boy if one of those kids go down, we really have a problem because their youth says a lot. Gotta make sure they get taken care of. So it becomes a situation when health becomes a motivator

in whatever you do and everything else is second. Doesn't make a difference what comes next./

C reflects that his health as well as his children is important given their caregiver responsibilities.	They have to take care of themselves in order to continue caring for her.	The delicate balance of ongoing care depends upon all of their health.
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And I tell you, we've been through four or five caregivers and they were from commercial companies and I was very dissatisfied with them. They have certain restrictions, they can't lift the patient they can't do this they can't do that and in Lois' case you have to help her to the bathroom, and now the gal we've got is on her own isn't part of a company and I'm not concerned about it because this gal used to wrestle cattle in Nebraska and used to work for a veterinarian here in town he passed away she is just a godsend she comes in 4 days a week, 4 hours a day; will clean her, make her meals, talk to her, she is great. I want to keep that one going, always fear that will end one day./

C says he hasn't been satisfied with caregivers from commercial companies, they have been through 4 or 5 and they have too many restrictions. The caregiver they employ 16 hours a week had wrestled cattle in Nebraska and worked for a local veterinarian. She makes meals, talks to his wife and he is afraid it may end someday.	After trying around 5 caregivers from commercial agencies, they found a wonderful helper whose background was rustling cattle and veterinarian's assistant.	They have excellent help now but this might end at any time.
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These commercial people I just have not had good experience, I think they mean well I'm not sure they're trained and you know yourself, just because you go to an Alzheimer's class doesn't make you an expert in Alzheimer's and somehow they market that and that's wrong./

C says he just has not had good experience with commercial caregivers. They are marketed as trained Alzheimer's care givers and he doesn't think a class makes them an expert.	They have tried outside resources specifically marketed as Alzheimer's patient support, which he feels is dishonest; they had too many restrictions which demonstrated to him his needs were not understood.	Outsiders are difficult to trust with care giving, not just anybody can do it.
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So we're lucky with this caregiver. I hope she stays with us. If she left for some reason we'd have to scrounge for something else. It's not bad duty, 4 days a week, 4 hours a day, and Lois is fun to be around. This caregiver and her they talk, talk, talk, talk, talk, and when we get her at night, she's all worn out, which is okay as long as she is communicating to

someone. And she loves this gal. She knows when she's there; senses what's going to happen. So, she's probably better than the rest of us. We're learning./

C feels lucky to have the caregiver they have, and he doesn't think the work is hard, maybe even fun because she and his wife do a lot of talking and then at night his wife is worn out. His wife feels understood and loves this caregiver,	It was luck finding this caregiver who has such good rapport with his wife.	Rapport is important.
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The only comment I have is, it's 24/7. You never get a break. Yes, I'm here doing taxes, but then it's back to that. I think we're unique. I'm damn proud of it. We'll keep doing it. There's no reason for us to change our course. I don't know how long it will last; we will have fun doing it. We've gone through the depression stage. We are at the realistic stage. We're going to take care of it. You know your whole life is dedicated to it and I'll be damned if I give up at this stage. So that's my comment from the caregiver side. That's life./

C repeats the 24-hour commitment, says one never really gets a break, he is proud of what they do. They have been through different stages and he'll be damned if he gives up now. It is all part of life.	Reinforces the 24-hour care grind, his pride, and uncertainty of time. Mentions they've been through a stage of depression, which has past. Now they are realistic; he has dedicated himself to this course of action and will not stop now.	
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You read some of this stuff that it goes in phases, but if you don't read this stuff, damn, the next phase will blow your socks off. You don't know what to expect. You read. Unless you attend the Alzheimer's readings and talk to those people, you wouldn't know./

C reports the importance of educating yourself about Alzheimer's in order to know what to expect.	You can learn from the experience of others.	
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That's been the toughest thing for us is what's next. We've been through the violence we've been through the language problem don't know if there's anything left or not we're going to continue holding steady./

C says the toughest thing has been wondering what the next stage is, at this point he doesn't know if there is a next stage	They are facing the unknown next stage or phase or maybe there isn't anything coming next.	Total care might be the last stage.
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Yeah, the memory is less, that's true, and it's hard to go through life without a memory. But as long as someone is taking care of you, it's okay. It's not what you anticipated that's for

damn sure, but when you get the quality care we're giving her, I think it's unsurpassed. It's very rare you get three or four caregivers. That's unusual./

C acknowledges the situation must be hard for his wife, and she had not anticipated this, but this situation is the best it can be.	They are all making the best of the circumstances (including his wife) to provide quality care.	Reflects on the quality of life—not ideal but knowing you're being cared for by those who love you is quality.
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We all have got our assignments we know what we're supposed to do, it's like a job, mine is laundry, I used to take her breakfast, I don't do that anymore because she sleeps 'til noon, I don't know if that's good or bad on the other hand it gives me a break, doesn't seem to hurt her one iota. Eats like a horse, sleeps like a baby, so I think that could go on indefinitely./

C says they all have their role responsibilities. He notes his wife sleeps and eats well.	They have their tasks and there is little divergence from the routine which has no end in sight.	
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She was the secretary for Dave Bliss and Basketball at the University. She liked college kids. She loves kids. She's always been that way. It's kind of interesting, even today she'll watch NCAA basketball and every once in a while, she'll catch a glimpse and recognize it's basketball—its final-four time—and in a moment, it's gone just like that./

C says his wife had been secretary for the local college basketball team and even now once in a while she seems to be aware of basketball.	Bouncing around in time and finding a residual in her current awareness.	Reminisces, finding joy in the possibility his wife can feel back to the good times.
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So we're happy, we're doing just fine. I can't speak for everyone. They were in athletics. (Daughter) missed the Olympic volleyball by two. If you have the attitude, you'll make it, I see it all the time with taxes, with the kids; somehow you'll recover. I say she was the basketball secretary. They used to have basketball shorts and what it said was, this was David Bliss the coach, "Attitude is everything." And when you think in your own life where you are and where you're going, you have to have the right attitude and if you do, it will work. But if you have a crappy attitude, you can ask, why did I get these crappy cards? It doesn't matter why. You just better perk up the attitude and take care of it. Life is not perfect. No one said it is. No one promised it. I've seen it in business, I used to work for a big company if you have the right attitude it's incredible what the team can do it will just blow your mind and I think that's our case here, the attitude and how we deal with it. Keep a sense of humor, keep your nose to the grindstone, and you'll be okay. And I'm sure you've

probably found that in your career. We have two daughters in education. I was never in education, but I used to teach part time, so that's it. Did I help you at all?/

C admits he can't speak for all of them but imagines they are all happy and doing fine. He attributes this to a positive attitude and working hard. Life isn't perfect you can't control the cards you are dealt.	Attitude is a major factor in any of life's successes.	The only way to maintain the conviction and dedication of their care giving is to maintain the proper attitude and not complain.
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Interview 6 Structure

Rephrasing of last iteration of meaning units:

There was a specific time and set of circumstances that seemed to begin the current state of affairs. Three family members and a hired part time helper provide 24-hour coverage. Comorbidities add to the physical/ lifting aspect of care as the disease progresses. The care is highly organized the same routine from day to day with specific times and tasks for each of them. One person could not do it alone. His wife's care is the focus of his, his son's and daughter's lives right now. His wife went through typical stages of disease and is now calm. They provide custodial care for his wife who is docile and no longer speaks. He holds onto memories of the way she was. There are different levels of family involvement; the in town kids provide daily care; the out-of-towners, sporadic. There is no moral alternative to the situation; he is doing the right thing. When his wife was not herself he communicated her situation via calling cards. He reaches out via cards for validation from his peers. His wife has become "they" as he followed stages of Alzheimer's. ("Yeah, no they don't have any inhibitions."). He deals with the uncertainty of the situation on a daily basis. Institutionalizing his wife has bad connotations, representing abandonment vs. his responsibility to care. The care giving is in the context of his ageing, which he balances, with the respite of lifelong passion for work. Care giving particularly incontinence care demands a routine set of tasks including laundry. The family involvement keeps his children engaged in a semblance of maintaining his wife's previous routines. For 9 years the focus of their lives has been care giving. The situation keeps getting harder as the dementia worsens. Although his wife no longer talks he recalls humorous things she has said in the course of the dementia. Memories of who she was fuel his perseverance. Round the clock custodial care is easier with her passivity. The dementia has progressed to the point she does not react strongly anymore, making care easier as far as her emotional response. They care for the spirit of the person she used to be. There are outsiders to the situation that they have had to insulate her from. He expresses pride in his wife's resistance to her situation and the outside world and feels validated when his peers recognize his situation. Many people are ignorant regarding Alzheimer's—he has worked at explaining the situation. There have been significant behavioral challenges that have isolated them from mainstream living. They stick together and buffer his wife in order to keep long-term routines in place. They have overcome challenges. The background is ignorance regarding dementia particularly in younger people. The current organized routine of assigned care giving responsibilities can continue indefinitely as long as there's no deviation from the course. The situation is tentative and fragile. It may go on for another 6 or seven years so humor is very important. A "home" represents abandonment to strangers. The person for whom they are performing this service may be unaware of their effort. Small indications of appreciation or awareness are amplified. Her self/personhood is almost completely gone. He contradicts himself and indicates examples of his wife asserting her personality. She does this with refusal of certain foods. He is reminded daily of happier times and his wife's spirited responses to things she didn't like. There is comfort in knowing he is not alone. Educating others adds to this. As long as his wife is aware of the care she is receiving he can continue indefinitely. Care giving is 24-hour vigilance and emotional and physical work. He is always on call. Remembering funny incidents helps hold the situation together for him. Institutions and homes are abandonment to strangers. He feels indebted to his wife for her years of

companionship. His children feel the way he does. His whole life is about caring for his wife. Respite time is important and keeps them “recharged.” His memories balance the current situation. He keeps the current situation balanced by their lives together over time. He is uncertain of her current awareness of situations she has loved and has been very comfortable in before. It is important to hold out hope that there is some awareness. “Institutions” are impersonal and don’t provide good care. His wife is emotionally responsive even if unable to recognize her children. Acknowledges the deeply distressing nature of the experience for all of them. Concerned that he has had to lie to his wife at times to keep her comfortable. He is ageing which makes all physical effort harder. The work is physically demanding. The routine schedule gets boring and respite is important. Apologetic about needing respite—rationalizing that he has had cancer, needs to take care of himself in order to take care of her. The delicate balance of ongoing care depends upon all of their health. They have excellent help now but this might end at any time. Outsiders are difficult to trust with care giving, not just anybody can do it. Rapport is important. Reinforces the 24-hour care grind, his pride, and uncertainty of time. Mentions they’ve been through a stage of depression, which has past. Now they are realistic; he has dedicated himself to this course of action and will not stop now. You can learn from the experience of others. They are facing the unknown next stage or phase or maybe there isn’t anything coming next. Total care might be the last stage. Reflects on the quality of life—not ideal but knowing you’re being cared for by those who love you is quality. They have their tasks and there is little divergence from the routine which has no end in sight. Reminisces, finding joy in the possibility his wife can feel back to the good times. The only way to maintain the conviction and dedication of their care giving is to maintain the proper attitude and not complain.

Gradually over the last 7 years, since a period of anemia, he, an elderly man with his own medical problems, has been caring for his wife who has cognitively and physically declined and is now in a wheelchair, requiring total care under his control. His children assist in this care that is 24 hours a day, 7 days a week, basically the same physically demanding routine that is drudgery and boring. This has become the focus of their lives. There is no end in sight so they maintain their course citing humor and maintaining a positive attitude as tools against such poor prognosis. He grieves for the loss of who she used to be. They schedule respite breaks aware that ongoing care requires that they stay healthy.

He accepts this responsibility as part of life and his moral obligation. He sees nursing home placement as abandonment to impersonal institutions that provide poor care. He doesn’t trust outsiders with care giving, had tried some specifically trained in dementia care who were not helpful, unable to provide the care they way his family does.

He feels indebted to his wife for years of companionship. At times he refers to her as part of “they”—meaning the demented, and how this helped him deal with her irrational behavior. He wavers between thinking that his wife may be completely unaware and believing that her affect and ability to feel their love is intact. He and his children care for the spirit of who she used to be, maintaining long-term family routines she used to enjoy. He reminisces remembering her spirited approach to life, which helps bolster his day-to-day efforts. He amplifies any indications that his wife’s old self is there. He props her up with

his reminiscences and maintenance of her former routines, to maintain her existence for himself.

His wife has been through “stages” he understands through his reading, including disinhibition when her comments and behaviors presented difficulties being in public. They had to insulate her from this. This was isolating and illustrated the general ignorance of the population regarding dementia. He felt validated and less isolated when able to address some of this ignorance as well as when his situation was understood and admired by his peers. He is proud of what he is doing.

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