

AN INVESTIGATION OF SPIRITUALITY IN CAREGIVERS
FOR SPOUSES DIAGNOSED WITH
ALZHEIMER'S DISEASE OR RELATED DISORDERS

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A
DISSERTATION

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ABSTRACT

AN INVESTIGATION OF SPIRITUALITY IN CAREGIVERS FOR SPOUSES DIAGNOSED WITH ALZHEIMER'S DISEASE OR RELATED DISORDERS

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This study explores the impact that spirituality has on the life of an Alzheimer's and Related Dementia (ARD) spousal caregiver. Based on a phenomenological methodology, 11 ARD caregivers described how their spiritual lives influence their daily experiences in caring for their spouse. Through discussion with these participants, certain thematic elements emerged: *Spirituality versus Religion*, *Trusting God*, *Don't Ask Why*, and *Growth and Understanding*.

The investigation indicates that spirituality primarily impacts the daily experiences ARD spousal caregivers by allowing them to *Let Go and Let God* instead of dwelling on asking God why their spouse developed ARD. This ability has provided these caregivers with a reason to continue living efficiently and effectively day after day despite the difficulties often associated with this role.

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Forever in debt, and forever in thanks,

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CHAPTER 1

THE PROBLEM AND JUSTIFICATION FOR THE STUDY

Introduction

What role does spirituality play in the life of a caregiver who is married to a person with Alzheimer's or related disorders? This study attempts to answer the question by exploring the lived experience of spirituality in spousal caregivers of individuals with Alzheimer's and Related Disorders (ARD), and it emanates from the realization that some caregivers report that they rely on aspects of spirituality to help them cope with their situations and to reduce the emotional and physical effects that frequently accompany this role (Chang, Noonan, & Tennstedt, 1998; Pinquart & Sörensen, 2003). Few studies, however, describe what is meant by the concept of spirituality, what its meaning is for ARD caregivers, and how it is implemented in the everyday lives of these caregivers (Stuckey, 2001). This study is intended to help fill that gap in the ARD caregiver literature.

Description and Impact of Alzheimer's and Related Disorders

Alzheimer's Disease (AD), a progressive neurological disease, was first described by Alois Alzheimer during a lecture to German physicians in 1906 (Thompson, 1997). In his case description, Alzheimer described a disease that included memory loss, cognitive and language deficits, auditory hallucinations, delusions, paranoia, aggressive behavior, and two brain abnormalities: miliary bodies and dense bundles of fibrils (Berrios, 1994). Today, these two biological hallmark features of AD are more commonly known as neuritic plaques and tangles (Blennow, deLeon, & Zetterberg, 2006). In ongoing efforts to further distinguish AD from normal aging deterioration, researchers and clinicians

have also established the presence of multiple cognitive deficits in the diagnosis of AD. According to the most recent version of the *Diagnostic and Statistical Manual of Mental Disorders* [DSM-IV-TR], these deficits include memory loss and one or more of four other cognitive disturbances: aphasia (language disturbance), apraxia (motor activity disturbances), agnosia (inability to identify objects), or disturbance in executive functioning such as planning or abstract thinking (American Psychiatric Association [APA], 2004).

Although AD as a diagnostic classification has been around since 1911, the prevalence (number of people diagnosed with AD at a given time) has been on the rise in recent decades (Alzheimer's Association, 2006). The prevalence is further exacerbated because AD cannot be fully diagnosed unless an autopsy is performed (Holtzer et al., 2006; van der Flier, Barkhof, & Scheltens, 2007). Due to this situation, researchers have begun to use the term *Alzheimer's Disease and Related Disorders* (ADRD) to refer to this category of diseases. Despite a continuing debate about whether this prevalence is due to better diagnosing or to an actual increase in the cases of ADRD, the fact remains that the number of Americans diagnosed with ADRD is growing rapidly. The Alzheimer's Association presently reports that ADRD affects the memory and cognitive abilities of approximately 4.5 million Americans. Putting this number in perspective, 1 in 10 Americans has a family member with ADRD and 1 in 3 knows someone with the disorder. The association literature also projected that the number of people with ADRD will continue to grow unless a cure or a method to prevent this debilitating disease is discovered. Brookmeyer, Gray, and Kawas (1998) estimated that the cases of ADRD in the United States will likely increase to 8.7 million cases in the next 50 years.

This increase will generate substantial additional burdens for both the patient and the informal family caregivers who typically provide most of the daily care required by individuals with ADRD (Langa et al., 2001). For instance, the National Institute on Aging (NIA) reported that the average lifetime cost of caring for someone with ADRD was approximately \$174,000 (Ernst & Hay, 2003).

Spousal Caregiver Distress

Within the family caregiver population, spouses make up the majority of caregivers (Allen, Goldscheider, & Ciambone, 1999), with wives more likely to be the primary caregiver (Houde, 2002; Neal, Ingersoll-Dayton, & Starrels, 1997). These wives and husbands often become so focused on their caregiving responsibilities that they pay little if any attention to the tremendous costs and risks involved in taking on this role (Mittleman, Roth, Coon, & Haley, 2004). For example, caregivers of a spouse with ADRD have been shown to have higher rates of depression, reduced life satisfaction, and increased physical health problems when compared with noncaregivers (Pinquart & Sörensen, 2003; Roth, Haley, Owen, Clay, & Goode, 2001; Schulz, O'Brien, Bookwala, & Fleissner, 1995).

As spousal caregivers provide the most comprehensive care for the longest periods of time of all family caregivers (Horowitz, 1985), they often encounter not only increasing caregiving responsibilities but also important changes to their marital relationship as the disease progresses (Stoller & Cutler, 1992). Over time, all these changes and responsibilities begin to take a toll on a spousal caregiver's health. Research has suggested that "elderly spouses strained by caregiving are 63% more likely to die during a given 4-year period than other spouses their age" (U. S. Department of Health

and Human Services, 2002, p. 2). Given this high mortality rate, many researchers have begun to focus on theories and techniques to assist caregivers.

Initially these theories of caregiving were based on a stress and coping framework (Lazarus & Folkman, 1991; Stolley, Buckwalter, & Koenig, 1999). Recently, however, this research has been expanded to include additional aspects of caregiving such as spirituality (Kaye & Robinson, 1994; Stuckey, 2001). Responding to this shift, two groups of researchers have explored the impact of spirituality practices on the caregiving relationship. Chang et al. (1998) provided insight into the role of spirituality among caregivers of elderly who were disabled, suggesting that religious/spiritual beliefs promote relationship satisfaction with the care receiver. In the same year, Tix and Frazier (1998) assessed the effects of religious coping strategies of patients undergoing kidney transplants, and reported relationship improvements when caregivers used religious coping strategies. While these studies were noteworthy, they did not incorporate the demands of a progressive illness that are common to an ADRD caregiver.

These increased demands were highlighted in the research of Straw, O'Bryant, and Meddaugh (1991), who found that ADRD caregivers have more unmet needs than do caregivers for other diseases. As a result, the role of spirituality may differ among caregivers of other illnesses. To understand better why these differences might occur, research has begun to focus not only on spirituality but also on describing what it is like to take on the role of caring for a spouse with ADRD.

The following passage from the life of Elbert, a minister, and Virginia, his wife who was diagnosed with AD before the use of the more inclusive diagnosis of ADRD,

portrays a personal picture of what it is like to be a spousal caregiver for someone with ADRD:

Somehow in the hurry of dressing Virginia nothing was working. I gave up smiling and started yelling at her...Her body shook, terrified. I cursed and yelled. I couldn't take care of her. I felt so bad I began to cry and apologize. I tried to hug her and she pushed me away. Then in a moment of reconciliation, she patted my shoulder and touched my face. Many times I realize that I'm moving toward losing my patience, but the memory of that single occasion brings me back. ...Each night after he pulls back their chenille bedspread and Virginia falls asleep, he goes back to his study. He spends an hour in the darkness, praying and working through any anger or frustration. Friends and family marvel at Elbert's serenity and stamina... Elbert said he is doing nothing extraordinary. It's just simple caring and reassuring. That's within the reach of everyone who loves someone. Trial and error have taught him the most. Knowing Virginia for 53 years helps fill in the rest.... He tries not to squelch any independence she shows, hoping he will help her retain it.... And he stopped trying to reason with her long ago. He assumes she lives "in a frightening world" where darkness has replaced knowledge, so he guides her through the days with nudges, embraces and murmured cheerleading.... "I try never to miss an opportunity to motivate and stimulate," Elbert said. "You talk about stopping to smell the daisies, well, we do that." Elbert regularly takes her to the movies, church, the beauty parlor and the Nelson Gallery. His rewards are the moments when her eyes are alert, her smile radiant, her hand tight in his. Pain mixes with joy. "I have thoughts like, 'If she

were functioning at full capacity, this would be such a great moment,” Elbert said. Then the practical side of me takes over and says, “that’s not possible. Skip that, Elbert.” We really lost Virginia three or four years ago, yet we’ve had these extra days together. We’ve been saying goodbye to each other for a long time. (Miller, 1994, pp. 38-39)

Lindgren (1990) pointed out that spousal caregivers of individuals with ADRD like Elbert in the preceding excerpt often practice unrelenting vigilance and have to adapt continually to the changing dependency of their spouses. During this process, spousal caregivers may experience “erosion of self, the feeling of becoming trapped, or that one’s identity has been completely submerged into the caregiving role” (Zarit, 1996, p. 142). As a result, spousal caregivers often become frustrated, frightened, and experience guilt and bitterness due to the increasing dependency of their spouses with ADRD (Chenoweth & Spencer, 1986). Due to emotional exhaustion and lack of personal accomplishment, these spousal caregivers also frequently experience burnout. Furthermore, they often become trapped inside their homes with few opportunities to change their situations by developing helpful social relationships (Lindgren). Another caregiver, Phyllis, described the isolated and stressful life of a caregiver this way:

Where am I?

Where did I go?

What happened to me?

I am a Caregiver

That’s who and what I am

Non-stop 24-7

A Caregiver

Get my meds

I need a drink

What's for lunch?

I had an accident

Oh well, more laundry, then when the kids were toddlers...

What time is dinner?

You just finished lunch

Where is me-lost for now

I am a Caregiver

Lunch with Jeanne-not today

Can't go anywhere

The collar & the rope are fastened to my very being

I feel the noose around my neck

Yes, I am a caregiver

What did I do to deserve this constant pressure & responsibility?

What did he do to deserve this [ADRD]?

My children & grandchildren are the oxygen that allow my soul to breathe and go

on

But, is it the disease?

Lash out, lash out

One bash to the head

You're stupid & don't understand

You have no compassion

You need classes to learn

My mouth is silent

His is raging

On & on and on

You don't listen

You don't understand

No, I don't understand

Life isn't fair

Nastiness is spewing out of your mouth

Like an erupting volcano

Another bash to the other side of the head

My very being is in pain

Where is your compassion?

I give my all and then give more

Another sleepless night

The exhaustion is physical

The mental tired is most draining

Another blow to the head

The tone of voice & words are so hurtful

It's not fair

I realize now it doesn't have to be. (Perry, 2005, p.73)

Although research continues to highlight the use of spirituality by caregivers of spouses with ADRD to cope (Stolley et al., 1999), a review of the literature indicated that there were only a limited number of studies that explore what the term *spirituality* means to caregivers of a spouse with ADRD or how they implement their concept of spirituality into their daily life (Stuckey, 2001). Due to that gap in the literature, this study was designed to expand the caregiver and spirituality research by exploring the concept of spirituality of caregivers who are spouses of individuals with ADRD.

Statement of the Problem

Spousal caregivers of individuals with ADRD cope with many stressors of caregiving, including financial concerns, physical and emotional strain, social isolation, and grief issues. A summary of research on caregivers listed 25 different burden issues faced by caregivers of spouses with ADRD (Reinhard & Horowitz, 1995). All these stressors tend to negatively affect the spousal caregiver. They often experience depression, anxiety, and a decline in physical health, primarily because caring for a chronically ill spouse with ADRD may last several years. The permanent nature of ADRD requires the use of long-term coping strategies.

An increased spiritual perspective has been shown to be an effective coping strategy in achieving greater well-being in grieving (Reed, 1987). Although spouses of individuals with ADRD describe a spiritual perspective as an important resource in their caregiving, little research has been done to explore what this means in the life of the caregiver (Robinson & Kaye, 1994). In order to focus primarily on the essence or structure of this shared experience, this researcher investigated the phenomenon of spirituality in caregivers of a spouse with ADRD using a qualitative phenomenological

design. Based on this methodology the study explored the following questions: 1) Does spirituality play a role in your life as a caregiver for a spouse with ADRD? And, if so, 2) what is that role? Further discussion of this methodological design and these questions will be found in Chapter 3.

Justification for the Study

Historically, spirituality and religion have been largely viewed and conceptualized in a negative manner within the field of counseling; thus, little attention has been given to the investigation of these matters within the literature (Miller & Thoresen, 2003). Over the last 20 years, however, there has been a major perspective shift within the counseling community. These past two decades have been marked by a decided increase in acceptance, appreciation, and interest in spirituality by mental health professionals (Miller, 1999; Miller & Delaney, 2004; Richard & Bergin, 2000; Shafranske, 1996; Sperry & Shafranske, 2004). Along with the newly acquired perspective has come an impressive rise in the number of publications focusing on spirituality and spiritual issues in the literature. Much of this literature has been published in peer-reviewed journals such as the *Journal of Mental Health, Religion & Culture*, *Journal of Religion and Society*, *Journal of Psychology and Christianity*, and the *Journal of Psychology and Theology*.

These specialized journals have been critical to enhancing the understanding and knowledge of spirituality. Many mental health professionals have come to rely heavily upon these distribution outlets to guide their work with their clients' spiritual issues. Clinicians have benefitted from the development of these journals and the research ideas therein. As is the case in many peer-reviewed publications, qualitative research has been

remarkably underrepresented in these journals. The preponderance of research published in spirituality-oriented journals has been quantitative in nature. This is noted not to criticize these journals or quantitative and theoretical activities, but rather to emphasize the potential for the use of alternative methodologies in the investigation of spiritual issues.

Recently, there has been a call for qualitative research by several prominent leaders in the field of spirituality (Plante & Sherman, 2001; Richards & Bergin, 1997). Richards and Bergin, for example, urged psychotherapists to “study spiritual issues in personality and psychotherapy creatively and rigorously using qualitative methods” (p. 330). Other researchers have also made a case for why qualitative research should be emphasized in the spirituality literature. Farnsworth (1990) affirmed that the phenomenological approach is the “most effective and efficient method for understanding and validating religious experience because religious experience is subjective in nature, involves both emotion and reason, and therefore, requires meaningful personal participation of the experiencer” (p. 236). Another researcher, Stringham (1993), suggested that qualitative methods are well-suited for investigating abstract processes and for generating theory on spiritual topics. Based on these recommendations and findings, this study used the qualitative approach of phenomenology to explore the lived experience of spirituality in the lives of spousal caregivers of individuals with ADRD.

Limitations

The study has limitations that are inherent to its design and methodological research style. From a phenomenological approach, this researcher attempted to be sensitive to the gathering of information as well as to the context of the information, and to an awareness of personal biases inherent in this type of research. In addition, it is important to note that the researcher's introduction of the construct of spirituality influenced the results of this study. As with any research using a predetermined construct like spirituality, this study may have inevitably led participants to discuss the construct, even if they would not naturally think in such terms. As a result, another limitation of this study is that the researcher's construction of reality is mingled with the participant's interpretations of reality (the lived experiences of spirituality in spousal caregivers of individuals with ADRD), producing yet another understanding (the interpretation by this researcher of others' views filtered through his own).

Since this unique experience could never be replicated exactly, generalizability to other populations was minimized. Generalizability to other populations was also limited since participants were recruited using purposeful and nonrandom sampling. This methodology brings in the human element, fraught with personal biases (either conscious or unconscious), and may have prevented different experiences from being realized through this study. Participants may only include more social or active individuals, or individuals with only positive or negative stories to tell. Inherent to this type of sampling, again, is a minimization of generalizability as well as the introduction of the human element—conscious or unconscious bias.

As the meanings around the caregiver experience serve as tenets of each individual's socially constructed reality, the reader is reminded that it is but only one of many possible constructions. Unlike the scientific approach where "measurements and analysis of causal relationships between variables" (Denzin & Lincoln, 1994, p. 4) are purported to be within a "value-free framework," this investigation provides only a beginning for conversation and inquiry in an evolving historical world. This researcher attempted to provide insight into the creation and process of each participant's personal and social experience and how it is given meaning. However, one significant limitation to this methodology was that the participant may have chosen to withhold or not share information regarding the phenomena due to discomfort with the interviewer or setting. As a result, the meanings may be based only on incomplete information.

Definition of Terms

Alzheimer's Disease (AD)

Named for its discoverer, German neurologist Alois Alzheimer, Alzheimer's disease is a progressive neurological disease characterized by memory failure (primarily short-term memory), confusion, disorientation, restlessness, agnosia (inability to identify objects) speech disturbances, inability to carry out purposeful movement, delusions and/or hallucinations (Anderson, Anderson, & Glanze, 1998). The presence of AD is determined by a diagnosis following a physical examination to rule out reversible causes of memory and behavioral dysfunction, with the understanding that a definitive diagnosis cannot be made except through an autopsy. AD is the most common form of dementia (>65%), and presents in midlife with slight impairment in memory and behavior, with symptoms worsening generally after the age of 70. The pathology of AD consists of

miliary plaques in the cortex and fibrillary degeneration in pyramidal ganglion cells. Symptoms frequently present at onset with the inability to assimilate new knowledge, recall words, and orient to the environment. Curative treatment is not available, and death usually occurs 8 to 12 years after the onset of symptoms.

Alzheimer's Disease and Related Disorders

Alzheimer's disease and related disorders are progressive organic mental disorders characterized by chronic personality disintegration, confusion, disorientation, stupor, deterioration of intellectual capacity and function, and impairment of control of memory, judgment, and impulses. Alzheimer's-related disorders are organic forms of dementia, generally considered untreatable, progressive, and irreversible. (Anderson et al., 1998, p. 457-458)

“The most common form of ADRD is Alzheimer’s type dementia” (Anderson et al., p. 68). Other related disorders include vascular dementias such as multi-infarct dementia and Binswanger's disease, frontal-temporal dementia, and Lewy-body disease. These conditions generally follow the same course as Alzheimer’s disease in cognitive decline, behavior manifestations, and length of illness. Thus, it is expected that caregivers for related disorders will experience very similar stress reactions to their caregiving role. Related dementias do not include reversible dementias such as depression, thyroid dysfunction, and rare dementias, such as Creutzfeldt-Jakob dementia, Wernicke-Korsakoff's encephalopathy, Hunnigton's disease, and normal-pressure hydrocephalus.

Caregiver

Caregiver is defined as one who contributes the benefits of medical, social, economic, or environmental resources to a dependent or partially dependent individual

(Anderson et al., 1998). While the term care is often associated with a regard coming from desire or esteem, it has other subjective connotations—suffering of mind, a disquieted state of mixed uncertainty, apprehension, and responsibility, or cause of anxiety. Active associations include being in charge of another, as well as demonstrating painstaking or watchful attention of someone (Anderson et al.).

Spouse

Spouse is defined as the husband or wife of a person with ADRD. The couple must have had a legal marriage or have been married in a legal sense, such as common law.

Spirituality

The conceptualization of *spirituality* remains ambiguous in the literature. In a recent review of the spirituality literature, Sinclair, Pereira, and Raffin (2006) suggested that “the conceptual ambiguity of the term spirituality, while being filled with differences, is perhaps the single greatest point of unity in the literature, as researchers seemed to devote most of their discussion to the lack of conceptual definition” (p. 466). However, these researchers also suggested that

despite this ambiguity, three possible approaches to defining the term spirituality seem to be emerging: (1) recognition that the concept does seem to evade language and should therefore be treated contextually; (2) a broad definition of spirituality being proposed that is somewhat ambiguous; and (3) a concise definition being proposed that is restrictive. (p. 466)

This ambiguity is part of the tension between spirituality and science. In order to relieve that tension, *spirituality* in this study refers to beliefs and practices that connect a

person with a sacred and meaningful entity beyond him or her self. These beliefs and practices are thought to create and sustain a personal relationship with a supreme being and give meaning and purpose to life.

Religion

Writers even at the forefront of research in this area use the term *spirituality* interchangeably with *religion*, which can contribute to confusion when interpreting study results. To clarify the terms in this study, *religion* is defined as a particular doctrinal framework that guides sacred beliefs and practices in ways that are sanctioned by a broader faith community – a system of beliefs and practices that help structure how people worship. Although the terms are not mutually exclusive, religion emphasizes a communal type experience while spirituality emphasizes a more personal experience. For instance, one spousal caregiver described his ability to cope with the effects of his wife having ADRD in the following way:

I can see her brightness vanishing, but I love Rose [his wife] because she is so loveable. Nothing can ever change that. Not even this Alzheimer's disease. I believe that Rose's spirit is alive and well, in spite of it all. This keeps me going.

(de Geest, 2006, ¶11)

CHAPTER 2

REVIEW OF THE LITERATURE

Overview

In qualitative inquiry, the philosophical and theoretical foundations of the study are essential to the research question and design; so, for this study, the researcher first reviewed the models and theories of caregiving connected with Alzheimer's and related disorders (ARD). In addition, since this study focused on spirituality, the researcher then reviewed the conceptualization and effects of spirituality in caregiving with special attention paid to caregivers of individuals with ARD. Lastly, the researcher reviewed the specific area of research on spirituality in spousal caregivers of individuals with ARD. Both qualitative and quantitative methodology were considered in this review.

Alzheimer's Disease and Related Disorders Caregiver Research

Theoretical Models

Caregiving for Alzheimer's Disease and dementia is the most frequently studied type of caregiving represented in the literature (Schulz, Gallagher-Thompson, Haley, & Czaja, 2000). The outcome of this large body of research has been a strong consensus that caring for an individual with ARD is burdensome and stressful for the caregiver and contributes to higher rates of depression and anxiety disorders in ARD caregivers (Schulz et al., 1997; Schulz et al., 1995; Teri, Logsdon, Uomoto, & McCurry, 1997). This hypothesis, which provides a foundation for much of the caregiver stress research, was developed from the larger general stress and adaptation literature that has generally focused on two primary theoretical models: a wear-and-tear or a stress-process model.

Wear-and-tear models are based on the theory that caregiver health deteriorates the more care and the longer time care is provided (Haley et al., 1996). Support for this

hypothesis was found in studies showing that caregivers were less likely to engage in preventive health behaviors (Schulz et al., 1997), that they showed evidence of decrements in immunity measures when compared with noncaregivers (Kiecolt-Glaser, Dura, Speicher, Trask, & Galser, 1991), and that they experienced slowing of wound healing (Kiecolt-Glaser, Marucha, Malarkey, Mercado, & Glaser, 1995). The evidence for this theory also indicated that some ADRD caregivers are at increased risk for serious illness (Shaw et al., 1997), and one study showed them to be at increased risk of mortality (Schulz & Beach, 1999). Overall, the convergence of evidence from these studies would indicate that a meaningful risk for adverse psychiatric and physical health outcomes exists for a subgroup of ADRD caregivers, who sustain high levels of caregiving demands, experience chronic stress associated with caregiving, are physiologically compromised, and have a history of psychiatric illness (Burton, Zdaniuk, Schulz, Jackson, & Hirsch, 2003; Schulz et al., 1995).

Stress-process models, although building on research similar to the wear-and-tear models that concentrate on the negative outcomes of ADRD caregiving, focus on identifying the factors that likely mediate or intervene between the stresses of caregiving and subsequent ill effects (Gatz, Bengtson, & Blum, 1990; Haley, Levine, Brown, & Bartolucci, 1987; Pearlin, Mullan, Semple, & Skaff, 1990). Originally described by Pearlin et al., these factors include primary stressors (the care recipient's impaired condition or the caregiver's subjective emotional reaction to it), secondary stressors (problems arising as a result of caregiving but outside caregiving roles), and the resources available to moderate caregiving stress and outcomes. Consequently, the two models of caregiver stress mainly differ in that stress-process models view caregiver

stress as a more complex process with interrelated domains of sources, mediators, and manifestations, whereas wear-and-tear models simply view ADRD caregiving as a process that will eventually take a negative toll the longer the ADRD caregiver is in the role (Pearlin).

Despite this theoretical difference, the two models share two important similarities. First, both the wear-and-tear and stress-process models grew out of a similar large body of research which has revealed that caregivers to older adults with ADRD consistently report higher levels of burden and depression than noncaregivers (Schulz et al., 1995; Vitaliano, Schulz, & Kiecolt-Glazer, 1997) or caregivers to persons without ADRD (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999; Pinquart & Sörensen, 2003). Second, both models assume that these negative psychological outcomes are the result of a stressful caregiving situation. Indeed, studies using both types of models report higher stress among caregivers who spend more time providing care (Desbiens, Muller-Rizner, & Viring, 2001; Ory et al.), who help with more basic and personal activities of daily living (Pinquart & Sörensen), and who care for individuals with behavior problems (Hooker, Bowman, & Coehlo, 2002; Shanks-McElroy & Strobino, 2001).

One of the first researchers to separate the two models by describing the connection between caregiver stress, coping, and health was Folkman in 1984. This first *stress-process* model of ADRD caregiving was based on her previous work on coping with Lazarus at the University of California Berkeley (1980). The researcher's new theory used a rational approach to distinguish two major theory-based functions of coping: problem-focused, which involved addressing the problem causing distress, and emotion-focused, which is aimed at eliminating the negative emotions associated with

the problem (Folkman & Moskowitz, 2004). Examples of problem-focused coping include making a plan of action or concentrating on the next step, while examples of emotion-focused coping are engaging in distracting activities, using alcohol or drugs, or seeking emotional support.

The theoretical distinction between problem-focused and emotion-focused coping provides a useful way of talking about many kinds of coping in generalizations, and it is used extensively in the coping literature. Other conceptualizations of coping functions often fit these categories. For example, Billings and Moos (1981) proposed a three-factor conceptualization of coping consisting of Active Cognitive (e.g., tried to see the positive side; considered several alternatives) and Active Behavioral (e.g., talked with a friend, tried to find out more about the situation), both of which are problem-focused coping, and Avoidance (e.g., tried to reduce tension by eating more, got busy with other things to avoid thinking about the problem), which is emotion-based coping. Although other investigators (Gotlieb & Gignac, 1996) found that problem-focused and emotion-focused distinction provided a good starting point, they also identified meaning-focused coping as a different type of coping in which cognitive strategies are used to manage the meaning of a situation. These investigators found that meaning-making coping, including making casual attributions and searching for meaning in adversity, was caregivers' most frequently reported way of coping with the behavior of individuals with ADRD. Based on this research and others, Folkman later added to her previous work by proposing a meaning-making factor as a useful way to think about coping efforts in which the person draws on values, beliefs, and goals to modify the meaning of a stressful transaction,

especially in cases of chronic stress that may not be very affected by problem-focused efforts (Park & Folkman, 1997).

At approximately the same time as Folkman was adding to her original model, Aneshensel, Pearlin, Mullan, Zarit, and Whitlatch (1995) developed a new stress-process model of caregiving. Instead of looking at caregiving from a problem- or emotion-focused perspective, their model viewed caregiver stress as being based on stress proliferation and stress containment. According to this model, stress proliferation referred to the overflow of primary stressors in the life of the caregivers into other areas of life such as work and family. Primary stressors were identified as objective or subjective. Objective stressors pertained to direct activities of care, whereas the subjective stressors pertained to the caregiver's own feelings of being overwhelmed with caregiving. The second key concept of the stress containment model referred to the process of utilizing available resources to combat primary and secondary stressors that contribute to the caregiver's erosion of self-concept (Zarit, 1996). In this model, there are two identified resources that caregivers can utilize in the process of containment: material and psychological resources. Material resources referred to caregiver's financial and social support. Psychological resources were the style and the self-concept of the caregiver, how he or she coped with and responded to stressors, and the views or feeling of a sense of mastery (Aneshensel et al.; Stephens, Crowther, Hobfoll, & Tennenbaum, 1990).

The idea for the concepts of stress proliferation and stress containment developed from previous research that examined how caregiver personality affects the ability of caregivers to cope with their role of caregiver. For example, Reis, Gold, Andres, and

Markiewicz (1994) suggested ways in which levels of personality development might influence caregiver health, burden, and satisfaction with social support. Reis and colleagues concluded that caregivers who tended to be more neurotic expressed a higher level of burden in caregiving and were less likely to make use of social support to alleviate the burden. Results such as these have led other researchers to attempt a further breakdown of the stress-process model in an effort to determine the meanings of the various factors being proposed as components of these models manifested in caregivers of persons with ADRD (Janevic & Connell, 2001; Kramer, 1997; Vitaliano et al., 1991).

Caregiver Burden Research

One of the largest bodies of this factor-based research has focused on the concept of caregiver burden. Over the years, the construct of caregiver burden has been advanced as an all-encompassing term that refers to the financial, physical, and emotional effects of caring for an adult with a disabling condition such as ADRD (George & Gwyther, 1986). The definition and measurement of caregiver burden have received considerable research attention in the literature, resulting in subsequent refinement of the construct and more precise methods of measurement (Vitaliano, Young, & Russo, 1991). However, the prediction of what causes burden has proved to be more difficult to determine.

Models predicting caregiver burden and patient impairment, such that caregivers caring for the most impaired patients would report the greatest degree of burden, have been refuted in the literature (Hadjistavropoulos, Taylor, Tuokko, & Beattie, 1994; Haley et al., 1987; Vitaliano et al., 1991). Rather, the experience of burden appears to be affected by many factors, including the caregiver's available resources, such as social support and financial resources, coping abilities, feelings of self-efficacy, ethnicity, and

spirituality (Vitaliano et al.). Therefore, considerable individual differences appear in caregiver outcomes, leading to the observation in longitudinal studies that some caregivers appear to adapt to the challenges of caregiving over time even as the patient continues to deteriorate, whereas others report continuing and increasing strain and burden (Townsend, Noelker, Deimling, & Bass, 1989; Zarit & Zarit, 1986). How and why some caregivers adapt over time and others fail to do so remain some of the least understood, yet most important, questions in this research area (Vitaliano et al.).

Positive Caregiving Research. To gain a greater understanding of these individual caregiver differences and the variability in outcomes, there has been a recent focus in the ADRD caregiving literature on the positive aspects of providing care to elders (Kramer, 1997). Talkington-Boyer and Snyder (1994) critiqued caregiver research for its focus on individual aspects of caregiving in relation to various outcomes such as caregiver burden. These researchers, among others, challenged the notion that all outcomes of caregiving are negative or burdensome. Consequently, the researchers examined both negative and positive outcomes of caregiving. One of the measures used in the study was the Caregiving Appraisal Scales (Lawton, Kleban, Moss, Rovine, & Glicksman, 1989) which assesses caregiver appraisal using two positive factors (mastery and satisfaction) and two negative factors (burden and impact).

Results of this research demonstrated the value of assessing both the positive and negative aspects of caregiving, showing that as caregiver burden increased so did levels of depression. Research by Andren and Elmstahl (2005) also demonstrated that as caregiver burden increases, caregiver self-esteem, satisfaction with social support, and ability to problem-solve decreases. Other theorists, such as Kramer (1997) and Farran

(1997), have put forth the notion of caregiving gain, and have proposed that it be conceptualized as not merely the absence of negative outcomes, such as burden, but rather as the presence of feelings of satisfaction, personal growth, and the idea that caregiving can provide enhancement and enrichment of the caregiver's life. Farran even suggested that an existential perspective, in terms of a focus on understanding how some caregivers are able to find personal meaning through caregiving, can significantly enrich the understanding of the caregiving process.

This idea of finding personal meaning has also been highlighted in the life transitional model of caregiving which offers an alternative context in which the caregiving experience may be interpreted (Kramer & Lambert, 1999). According to this model, a transition is "a permanent sudden life change that has a major impact and initiates a period of dislocation and adjustment" (Wells & Kendig, 1997, p. 666). Therefore, becoming a caregiver, and ceasing to be a caregiver either by institutionalization or death of that person in care, constitutes a major transition that may be experienced by people involved with older adults (Wells & Kendig). Implicit in the application of the life transitions model to the caregiving context is the theory that this transition may be associated not only with negative but also with positive experiences (Kramer & Lambert; Wells & Kendig). That is, while caregiving itself may have negative consequences, the exit from this role may be accompanied by improvements in well-being (Seltzer & Li, 2000). As mentioned previously, this is a contrasting approach to both the stress-process and the wear-and-tear models that view the transition out of caregiving as an inherently stressful life event characterized by cumulative, negative physical and psychological health effects (Pearlin et al., 1990).

Ethnicity in ADRD Caregiver Research. Besides the existential and positive aspects of caregiving, another focus of recent research has been on examining whether caregiver stress and burden vary among ADRD caregivers of different ethnicity groups (Depp et al., 2005; Hinton, Franz, Yeo, & Levkoff, 2005; Janevic & Connell, 2001). In the comprehensive study of ADRD caregivers known as the Resources for Enhancing Alzheimer's Caregiver Health (REACH) program, ethnicity has been shown to be an important variable in understanding the caregiving process (McGinnis, Schulz, Stone, Klinger, & Mercurio, 2006; Shurgot & Knight, 2005). In a review of studies of ethnic differences in caregiving, Connell and Gibson (1997) reported that most studies use predominantly or exclusively Caucasian samples or do not report the ethnic background of study participants at all.

Studies that have directly examined ethnic differences have investigated primarily Caucasian and African-Americans, with the result that even less is known about the process of caregiving in other ethnic or cultural groups. Nevertheless, these studies have revealed interesting differences between Caucasians and African-Americans that warrant future research.

Despite demographic differences between groups that appear to predict a more favorable outcome for Caucasian caregivers, such as higher income, most, although not all, studies have found that Caucasian caregivers report higher levels of burden and depression than African-Americans even given equivalent severity of patient impairment (Lawton, Rajagopal, Brody, & Kleban, 1992; Miller, Campbell, Farran, Kaufman, & Davis, 1995). The explanation for these findings is unclear. It may be that African-American caregivers, who rely more on informal sources of support and aid than

Caucasian caregivers, have developed more effective coping strategies. On the other hand, one variable that has not been controlled for in this literature is the relationship between caregiver and patient.

In most studies, Caucasian caregivers are usually spouses of the patients, whereas in African-American studies as well as in other ethnic groups, caregivers are most often an adult child or other family member (Connell & Gibson, 1997). Because spouses tend to report more burden than adult children (Deimling, Bass, Townsend, & Noelker, 1989), what appears to be a difference between ethnic groups may be largely a function of the type of relationship between caregiver and patient. This variable should be examined more carefully in future studies. In addition, ethnic differences in producing what are perceived as desirable responses on questionnaires and in interviews require examination.

Intervention Research. The accumulating evidence of all these factors on the personal, social, and health impacts of ADRD caregivers has generated intervention studies aimed at decreasing the physical and psychological effects of caregiving (Acton & Kang, 2001). Building on both the wear-and-tear and stress-process models of ADRD caregiving, the dominant theoretical model of caregiver intervention studies is the *stress/health* model. According to this model, the primary stressors placed on the ADRD caregiver include the level of patient cognitive impairment, the frequency of patient problem behaviors (agitation, restlessness, wandering, aggression), and the number of hours per week spent providing instrumental or personal activities of daily living (bathing, dressing, shopping, housework) and helping the patient to negotiate the healthcare system (getting patient to physician appointments, taking prescribed medications).

Problem behaviors of the older adult are often the most frequently endorsed stressor of ADRD caregiving, even compared with provision of assistance with daily tasks (Schulz et al., 1995). These investigators pointed out that this model also suggested that ADRD caregivers evaluate whether these demands pose a potential threat and whether they have sufficient coping strategies or capacities. If they perceive the demands as threatening and their coping skills as inadequate, they will experience stress. The experience of stress was assumed to contribute to negative emotional, psychological, and behavioral responses that put caregivers at risk for physical and psychiatric diseases. Not illustrated in the model are numerous feedback loops showing how responses at one stage of the model subsequently feed back to earlier stages. For example, a negative emotional response to a stressor might subsequently increase the stressor itself or have a negative affect on the appraisal of the stressor.

Early intervention studies focused primarily on these caregiver appraisals of their resources and situation. These interventions involved mostly support groups, individual counseling, and educational approaches (Schulz & Martire, 2004). In their review of interventions for caregiver distress, Knight, Lutzky, and Macofsky-Urban (1993) pointed out that evidence from this first wave of research was inconsistent and showed modest therapeutic benefits as measured by global ratings of well-being, mood, stress, psychological status, and burden.

Recent research focusing on more rigorous study designs evaluated a broader range of intervention programs involving individual or family counseling, case management, skills training, environmental modification, behavior-management strategies, and various combinations of interventions (Brodaty, Green, & Koschera, 2003;

Schulz et al., 2000; Schulz et al., 2002; Sörenson, Pinquart, & Duberstein, 2002).

Evidence from these studies suggested that combined interventions targeting multiple levels of the stress/health model and multiple individuals simultaneously (caregiver and patient) produced a significant improvement in ADRD caregiver burden, depression, subjective well-being, perceived satisfaction, ability/knowledge, and sometimes, care recipients' symptoms (Schulz et al., 2002; Brodaty et al.). That is, interventions combining different strategies and providing caregivers with diverse services and supports tended to generate larger effects than narrowly focused interventions.

A persistent limitation of ADRD caregiver-intervention research has been that individual studies offered relatively small sample sizes, tested a limited range of intervention strategies, and were geographically bound (Schulz & Martire, 2004). Also, it has been difficult to identify the optimal mix of program elements for a given ADRD caregiver/care-recipient dyad, and the clinical significance of treatment effects has not been systemically evaluated (Schulz et al., 2002). Some of these limitations are currently being addressed in the most ambitious caregiver-intervention trial to date, referred to as REACH (Resources for Enhancing Alzheimer's Caregiver Health).

REACH is a unique, multi-site research program sponsored by the National Institute on Aging (NIA) and the National Institute on Nursing Research (NINR). Phase 1 of REACH was recently completed, and this phase tested several different social and behavioral interventions designed to enhance family caregiving for ADRD (Schulz et al., 2003). A total of 1,222 ADRD caregivers and care-recipients participated in this trial. Although different interventions were carried out at different sites, all sites used the same measurement protocol, thus enabling the researchers to carry out preplanned analysis to

assess the effects of active treatments versus control conditions, as well as to conduct statistical analysis to identify key elements of interventions that contributed most to positive caregiver outcomes (Czaja, Schulz, Lee, & Belle, 2003). The results showed that, among all caregivers combined, active treatments were superior to control conditions in reducing caregiver burden (Gitlin et al., 2003).

Based on the findings of Phase 1 of REACH, a new intervention that combines the most promising elements of the Phase 1 trial, was developed and is currently being tested. Informed by the lessons learned, the strategy being pursued in Phase 2 involves the assessment of caregiver risk in five domains derived from the stress/health model: safety, self-care and preventive health behaviors, caregiver support, depression and distress, and problem behaviors of the care-recipient (Schulz & Martire, 2004). For each area of risk, there are multiple intervention options as well as outcome strategies that may be implemented. At this time, results are just beginning to be published on this Phase 2 of the REACH study. The majority of these articles, as mentioned earlier, have focused on the role of ethnicity among ADRD caregivers (Depp et al., 2005; McGinnis et al., 2006; Shurgot & Knight, 2005). In addition to ethnicity, research has also found that the demands of the caregiver role were experienced differently by spousal caregivers (Barber & Pasley, 1995; Ory et al., 1990; Rankin, Haut, & Keefover, 2001).

ADRD Spousal Caregiver Research

Morgan and Laing (1991) examined the experiences of husbands and wives immediately following a diagnosis of ADRD. Through interviews with nine caregivers, three men and six women, two groups emerged based upon their reaction to, and coping with the diagnosis. Caregivers in the grief group focused on the loss of relationship and

went through a process of coming to terms with, and letting go of, the impaired spouse. Those in the role strain group focused on the increasing amount of responsibility they would have to assume and attempts to cope with the caregiving role through a process of hanging on. The researchers found that the primary factor differentiating the two groups was the quality of the marital relationship prior to the onset of ADRD.

Caregivers in the grief group described their relationships as close and loving, and their spouses as lifelong friends. In the role strain group, caregivers characterized their relationship before the diagnosis as conflicted and lacking in intimacy. The differences between groups appeared to affect the motivation of caregivers in providing care. The grief group was primarily motivated by love, whereas the role strain group was motivated by a sense of responsibility and duty. This study stressed the need for health care professionals to increase their awareness of the past relationship the caregiver had experienced with their cognitively impaired partner in order to understand influences on their present attitudes (Morgan and Laing, 1991).

Prior research by George and Gwyther (1986) pointed to a similar idea and cautioned clinicians to look beyond the objective functional status of the ADRD patient and to consider a broad view of the caregiver's subjective perceptions, personal characteristics, and social resources. George and Gwyther also highlighted that clinicians need to understand that demands and burdens of ADRD caregiving change over time. They even suggested that because of dramatic differences in ADRD spousal caregivers, a variety of programs are needed to adequately restore the well-being of these spousal caregivers and enhance their effectiveness.

Gold, Cohen, Shulman, and Zuccherro (1995) built on this research and examined burden among 118 spousal caregivers. These spousal caregivers were given an initial assessment and a follow-up assessment six months later. Findings reflected the result of previous studies which suggested that the quality of relationship prior to taking on the caregiving role and gender differences were key determinants of caregiver satisfaction. In other words, spouses who appraised their relationship before caregiving as more positive viewed the caregiving role less burdensome. Female caregivers in the study reported higher levels of burden, but also expressed a greater sense of enjoyment in caregiving. In addition, the study found differences in the effectiveness of social support among caregivers. An increase in the positive appraisals of caregiving was associated with an increase in the number of family and friends who provided social support. Yet, the amount of social support and its positive effect upon caregivers appeared to diminish over time as the conditions of the care deteriorated.

According to Carroll (1989), one reason given for this lack of social support in ADRD spousal caregivers was that the burden of caregiving for a spouse with ADRD is different from the burden of caregiving for a terminally ill or disabled spouse. As Carroll noted, this uniqueness is likely due to the fact that mourning is chronologically and emotionally amplified with Alzheimer's afflicted spouses since the caregiver is mourning the afflicted spouse while he or she is still alive. Additional research has shown that under these circumstances spousal caregivers progress through various stages: denial, overinvolvement, anger, guilt, and acceptance (Gruetzner, 1988).

At the beginning, when the first signs of Alzheimer's appear in the spouse, denial is common as the spouse's forgetfulness is excused and the seeking of help and/or

treatment is postponed. Denial of the problem often leads to family conflict as members disagree on the course of action or type of care necessary, which can create barriers within the family and/or the couples. Gruetzner (1988) described the next stage as overinvolvement, when the caregiver admits the existence of illness and attempts to meet the patient's every need to compensate for the loss the illness brings. As the ill spouse continues to deteriorate, the physical and emotional burden of caring advances the caregiver to the third stage, anger.

Gruetzner (1988) posited that the anger stems from feelings of abandonment when the caregiver is left helpless in the relationship, widowed while the partner is still alive. The caregiving spouse is endowed with a role change as he or she assumes many other responsibilities such as managing finances, making everyday decisions for both self and afflicted spouse, and in some cases also taking on the role of breadwinner. The caregiver is also robbed of his or her spouse's love – emotional support along with intimate and sexual connection – as well as long-anticipated plans for comfortable retirement. Anger may also be a result of misbehavior of the ill spouse because of deteriorating cognitive functioning. Gruetzner indicated that anger behavior on the part of the caregiver and feelings of losing control of one's emotions precipitate guilt, the next stage of caregiver adjustment.

In the guilt stage, Gruetzner (1988) found that the caregiver reacted to his or her own loss of control as well as anger. The caregiver may wish that the spouse be relieved of pain and die. In turn, the caregiver feels guilty for having these thoughts and wishes. It is common that “the powerful combination of unresolved anger and guilt they [the caregivers] feel... becomes overwhelming and develops into serious depression”

(Gruetzner, p. 92). As the caregiver struggles through the different stages, he or she comes to acceptance, realizing that the ill spouse may need care away from home. Acceptance, the final stage, often comes when the caregiver fully understands the process, development, and effects of ADRD.

Beyond the acceptance stage, as well as throughout the stages of adjustment to such a heartbreaking and burdening life circumstance, the caregiver wrestles with existential questions. Life and death issues are blurred and a deeper meaning for living with the dead becomes evermore desired as the spousal caregiver struggles to comprehend one loss after the other in the different stages of the spouse's deterioration, as well as within the caregiver's deterioration. One researcher, Seifert (2002), described this internal struggle and search for meaning as aspects of spirituality.

Spirituality Research

Spirituality and Caregiving. Reed (1991) seemed to agree with Seifert's (2002) research proposing that as adults grow older they tend to use spirituality as a means of coping with the aging process in general. In this research, Reed conceptualized spirituality as

the human propensity to find meaning in life through self-transcendence, it is evident in perspectives and behaviors that express a sense of relatedness to a transcendent dimension or to something greater than self, and may or may not include formal religious participation. (p. 15)

Studies have presented evidence that, although formal, organized religious participation decreased over time, personal religious or spiritual involvement may actually increase.

For those older adults who continued to participate in organized religious activity, such

participation generally became their most frequent social activity. Besides aiding older adults in coping with aging overall, Reed (1991) suggested that spirituality can play a role in resolving grief and bereavement issues, enhancing well-being, and decreasing depression.

This idea was developed from an earlier study where Reed (1987) examined the value of spirituality for terminally ill patients in developing greater meaning and well-being in their lives. In this study, Reed compared the spiritual perspective of terminally ill hospitalized cancer patients, non-terminally ill hospitalized patients, and healthy non-hospitalized individuals. Reed conceptualized spirituality as a broader concept than religiosity and as not necessarily involving participation in a religious organization. When defining spiritual perspective, Reed identified indicators such as prayer, reading and contemplation, a sense of closeness to a higher being, interactions with others, and experiences that reflected spiritual interaction or awareness.

In this study, 300 participants were equally divided among the terminally hospitalized, non-terminally hospitalized, and healthy non-hospitalized groups. Each participant completed the Spiritual Perspectives Scale, which was used to measure the saliency of spirituality, and the Index of Well-Being, which assessed satisfaction with one's present life. Results provided evidence that spirituality can play a potentially significant role in the lives of those who are facing death, as participants in the hospitalized terminally ill group indicated a greater sense of spirituality than those in the other two groups. Spirituality was also positively related to well-being among terminally ill cancer patients, whereas no relationship between spirituality and well-being surfaced among the other groups of participants (Reed, 1987).

In an earlier study, Wright, Pratt, and Schmall (1985) examined how the use of spiritual support helped to relieve caregiver burden. The authors described families and individuals who used spiritual support to cope as those who “seek advice from clergy, attend church services, participate in church activities, and express faith in God” (p. 34). Using the Family Coping Strategies Scale, the authors assessed the effectiveness of three internal coping strategies (confidence in problem solving, problem reframing, and passivity) and five external coping strategies (use of spiritual support, use of extended family, use of friends, use of neighbors, and use of community services) in relieving caregiver burden as measured with the Caregiver Burden Scale. All three internal strategies and two external strategies (spiritual support and use of extended family) were significantly related to caregiver burden.

Caregivers, who experienced more confidence in problem solving, were better able to reframe problems, made more use of spiritual support and extended family, and reported less burden. In contrast, an increase in passivity was positively related to higher levels of burden. In this study, Wright et al. (1985) defined reframing as “the caregiver’s ability to redefine a demanding situation in a more acceptable way in order to make the situation more manageable” (p. 34). It was suggested that spiritual support might allow caregivers to reframe their lives in a way that allowed them to find meaning in the losses they experienced. The authors concluded that “spiritual support is a valuable resource for families facing the stressful situation of caring for a dependent relative” (p. 36).

Building on these studies and others, Chang et al. (1998) hypothesized that religious and spiritual coping would influence caregiving distress indirectly through its effect on the quality of relationship between caregivers and care recipients. The

participants included 131 caregivers from the larger Massachusetts Elder Health Project. Religious/spiritual coping was measured with a single item from the Meaning in Caregiving Scale, and quality of relationship was assessed with five items from the positive affect measure of the University of Southern California Longitudinal Study of Three-Generation Families. Caregivers who used religious or spiritual beliefs to cope reported better relationships with the care recipients, which were then associated with lower levels of depressive symptoms. The authors acknowledged several limitations to the study, including the small number of items used to measure religious/spiritual coping and quality of relationship. Yet, they felt the research had helped demonstrate the value of spirituality in alleviating the stress of caregiving.

Stolley et al. (1999) applied spirituality research to ADRD caregivers and looked at how prayer and religious coping may provide caregivers of individuals with ADRD “with the psychological stamina to endure caregiving responsibilities” (p. 181). The Springfield Religiosity Schedule was used to assess religiosity of caregivers, while the revised version of the Jalowiec Coping Scale was used to measure caregiver coping. The study included 64 caregivers who were followed over a 12-month period. The Springfield Religiosity Schedule was administered at the beginning of the study, and at 3, 6, and 12 months. The Jalowiec Coping Scale was completed at the end of the 12-month period. Over the course of the study, 64% to 72% of the caregivers reported using spiritual beliefs and religious activities as coping mechanisms. Participants’ personal religiousness, especially the use of prayer, was cited as the most helpful form of coping. Organized religious activity was also an important, but less used, means of coping with the caregiving role.

Spirituality and Spousal Caregivers of ADRD Patients. Robinson and Kaye (1994) examined the relationship between spiritual perspective, social support, and depression in 17 caregiving wives of husbands with ADRD and 23 noncaregiving wives of healthy adults. The authors conceptualized spiritual perspective as a therapeutic coping strategy “when caregivers perceive forgiveness from God and reframe their caregiving as a positive experience” (p. 219). Robinson and Kaye hypothesized that increased spiritual perspective would be associated with higher levels of social support and less depression among caregivers. Each participant completed the Spiritual Perspective Scale as a measure of spiritual beliefs and behaviors and the Center for Epidemiological Studies Depression Scale. Three instruments were used to evaluate social support: the Global Satisfaction Scale, Expressed Support, and Social Network List. Results indicated a positive, but not significant, relationship between spiritual perspective and social support. A negative, but not significant, relationship was also found between spiritual perspective and depression. The research did support the hypothesis that there would be a stronger relationship between spiritual perspective and the other variables among caregiving wives than among noncaregivers. The findings may have been affected by the use of a small homogenous sample of caregiving and noncaregiving wives. The authors concluded that further research using a larger, more heterogeneous sample was needed.

Stuckey (1998) conducted a study that sought to examine aspects of church participation in individuals with ADRD and their caregivers. The study was directed at determining the meaning of the church for caregivers, how participation in church had changed since taking on the caregiving role, and which programs offered by churches

might be of value to caregivers. Interviews were conducted with 19 spousal caregivers and 21 clergy members. Using an issue-focused approach, common themes were identified from the interviews. Although none of the caregivers reported feeling alienated from church, the level of participation had decreased for many. Those caregivers who had actually increased their church participation did so because they received specific support (e.g., joining the choir to become an active member in church). Another theme that emerged from the study was the challenge to both caregivers and clergy in determining when churches should provide assistance. Most clergy expected family members to ask for help before becoming involved, whereas caregivers were often ambivalent about seeking help. The author concluded that churches have an important role in providing support to caregivers, when given the opportunity.

In a study of 30 husband and 30 wife caregivers, Rudd, Viney, and Preston (1999) examined how the differences between gender and place of care might affect four states of grief: anxiety, sadness, anger, and guilt. As part of the research, participants were asked to rate (a) the amount of external spiritual support they received, (b) the importance of external spiritual support, and (c) the importance of support from internal spiritual resources. In this study, wife caregivers showed a significantly higher level of anxiety than husbands, yet when the importance of spirituality was factored in, the difference between men and women lost its significance. Likewise, it was found that the significantly higher level of anger expressed by wives diminished as the importance of spirituality in their lives increased.

As part of developing a profile of caregivers whose care recipients had died, Wyatt, Friedman, Given, and Given (1999) examined the role of spirituality in dealing

with caregiver bereavement in a study that included 124 caregivers within three months of their care recipient's death. Eleven items with a 4-point scale that sought responses ranging from *never* to *always* were used to measure caregivers' level of spirituality. High scores were associated with a stronger sense of spirituality. As caregivers' sense of spirituality increased, their depressive symptoms, negative reactions to caregiving, and perceived burden of care decreased significantly. An increase in caregivers' spirituality was also significantly related to greater positive outlook and caregiver satisfaction with support from others.

Summary

The review of the literature suggested that taking on the role of caregiver to a spouse with ADRD was commonly a stressful experience. These caregivers were not only shown to have higher rates of depression, burden, and anxiety but the research also suggested that the mortality rate of caregivers was higher than the rest of the population. To reduce the stress, the literature showed that many caregivers turn to spirituality to assist them in coping with this role. Despite a growing body of research that suggested spirituality is a vital component of many caregiver's lives, only a limited number of studies have examined the lived experience of spirituality in caregivers of spouses diagnosed with ADRD. It was the intent of this researcher to begin to fill that gap in the literature.

CHAPTER 3

METHODS

The approach that guided this research on spirituality in spousal caregivers of an individual with ADRD is interpretive phenomenology. This chapter describes the guiding principles of phenomenology and the methods the researcher followed in conducting this study.

Research Design: Assumptions and Rationale for Design

Interpretive phenomenology evolved from Heidegger's views of phenomenology, which focused on the idea that "we and our activities are always in the world" (Heidegger, 1962, p. 85). In other words in phenomenology, "we do not study our activities by bracketing the world, rather we interpret our activities and the meanings things have for us by looking to our contextual relations to things in the world" (Heidegger, p. 87). Thus, Heideggerian phenomenology provides a way of "letting the manifest in itself be seen from itself" (Heidegger, p. 95). Interpretive phenomenology builds on this philosophy and is a method for unfolding, breaking apart, and revealing what is concealed about a phenomenon, or what Heidegger terms manifest (Conroy, 2003). In this study, the concealed manifest sought to be revealed is spirituality of caregivers of spouses with ADRD.

To understand how this methodology was used to reveal the spiritual manifest of spousal ADRD caregivers, the following Heideggerian and interpretive phenomenological principles are important to highlight. The first principle refers to the ideas of interdependence, background, and awareness and states that

we exist in a world where there is reciprocal interdependence between self, others, and objects, which slowly come into our awareness as the need arises.

Things show up as they are against the “background,” which is the place where the mindless everyday coping skills, discriminations, and practices into which we are socialized are situated. We use our everyday coping skills or tools without mental representations... In other words, we continue to interact with people and objects in our everyday existence without thinking about what we are doing until we are stimulated by the unusual. At the point when we become aware, at some level, of what we are doing, we change our level of awareness and way of interacting to fit the context and make it all work. (Conroy, 2003, pp. 6-7)

The second principle highlights the idea that our background is composed of past, present, and future, and through interpretation, meanings are constructed. This principle states that

in the background of our existence is a web of relations where something becomes intelligible through the hermeneutic task of interpretation that incorporates historicity and forestructures of understanding. Being is constantly interpreting the meaning of things though not always aware of this work. We are born into a world that existed before us, and implicitly pick up or assume the meanings the world has taken on (Past), interact with the world as tempered by the past and our own experience with the world (Present), and project what we will do and be in the future (Future). Interpretation is an ongoing and evolving task. It is an interactive act because persons form an integral part of a communal world, and do not exist as separate entities; the world and the individual co-constitute meanings or understandings (co-constitution). Our meanings are not constructed as individual thinkers without relation to other people; we are always

in relation with others. Our understanding and interpretation of the world is co-constituted and synergistic (Conroy, 2003, p. 9).

The third principle explains how interpretations are developed using the hermeneutical circle and subsequently the hermeneutical spiral. This principle states that the hermeneutical circle made famous by Heidegger (1927) is the circular form of interpretation shared between persons in their interactions. It is by definition a closed loop that needed loosening without losing its interactive possibilities and interpretive nature. Opening the hermeneutical circle into a spiral (Conroy, 2001; Heidegger, 1998) releases interpretive research from a closed loop of enquiry represented by the circle. The hermeneutical spiral 're-presents' the spiraling process of interpretation where the interpretations of a group of people build on each other's understandings over a period of time. This release from a closed loop of interpretation allows the research process to grow and include interpretation by others rather than just the primary researcher and study participants (Conroy, 2003, pp. 9-10).

Thus, interpretive phenomenology centers on ontological questions of what it means to be human; that is, what meanings human beings give to their lived experience (Conroy, 2003). Interpretive phenomenology is related to the symbolic interactionist principle that meanings are constructed and expressed through language (Martin, 2003). In this study, the researcher asked caregivers to "interpret" or put into words (i.e., express through language) their own understanding of spirituality, and he then "interpreted" or coded their words. Interpreting does not involve "reading in" an imposed meaning, but

rather is focused on revealing in the caregivers' own words – their definitions of spirituality related to caregiving for a spouse with ADRD (Gadamer, 1989).

In any type of research, the concerns for reliability and validity are important to clarify. Phenomenological researchers, however, have a different language for dealing with the issues of reliability and validity. This language is based on the concepts of trustworthiness and confirmability (Lincoln & Guba, 1985). Forms of research less concerned with meanings emphasize epistemological questions of how do we know what we know, but in this research, interpretive phenomenology provides the basis for investigating caregiver perceptions and meanings related to spirituality.

The focus of interpretive phenomenology is to describe directly the participant's lived experience, while attempting not to impose an outsider's perspective (Conroy, 2003). The unit of study in an interpretive phenomenological study is meaning rather than an object or a structure. Furthermore, the phenomenological tradition argues that the lived experience or the perception of the world as the individual lives it (which may not correspond with how the world actually *is*) is the only "truth" the qualitative phenomenological researcher seeks (Munhall & Boyd, 1993). In using this methodology, the researcher does not place his reality on the participant, but seeks to understand the participant's reality by explicitly reflecting his or her own potential for bias (Kvale, 1996).

The researcher used a protocol to remind him of the notes he needed to take immediately before and after the interviews (Appendix A). Based on this idea, the central principles that guided this study included some hallmarks of the philosophical assumptions of phenomenology: (a) an emphasis on meaning, (b) gaining insight into the

insider's perspective and reality, (c) valuing of the lived experience, and (d) taking a stance of not knowing (Boss, Dahl, & Kaplan, 1996; Kvale, 1996; Munhall & Boyd, 1993).

Role of Researcher

In keeping with interpretive phenomenological methodology of becoming aware of personal biases and values that may have led to the research question and possible interactions with the resulting themes, the researcher has included a section on himself. This section includes the personal experiences that likely led the researcher to a professional interest with spirituality and spousal ADRD caregivers and it is provided to assist readers in understanding how the researcher constructed the study and the subjectivity that informed the experiential process of interacting with the data. For this reason, I am providing a concise narrative of my own subjective investment in the subject written in a first person, conversational style. It is the way I would tell my story if I were giving it verbally to present the clearest picture of myself as a researcher and professional.

I am a 38 year-old male, who for the last 7 years has worked as the Program Coordinator for a National Institute of Health funded grant to study the effects of a Stress-Busting intervention for ADRD caregivers. In this role, I have performed various jobs (presentations, data input and analysis, report writing etc.), however, the one job I have enjoyed and which has taught me the most is working directly with ADRD caregivers. Over the years, I have developed a close professional relationship with most of the 200 participants who have gone through the Stress-Busting intervention. This relationship developed naturally out of my role in recruiting and leading participants

through the psycho-educational support group, which is part of the intervention. During these group meetings, which meet for 1.5 hours once a week for nine consecutive weeks, ADRD caregivers often share some of their most intimate details with the group and me. I believe these details are revealed in the attempt to be heard and to ultimately find someone who understands and can help to relieve some of the doubts, stress, guilt, and isolation associated with this role.

Over the years, these caregivers have taught me far more than I have taught them. Some of the many lessons I have learned include the value of listening to another fully without interruption, the meaning of sacrificing your life for another human being, and multiple ways to stay connected to someone with ADRD. How ADRD caregivers manage to remain connected to the person they care for as the illness progresses has intrigued me over the years. Somehow, these caregivers manage to remain connected despite the reality that the person they are caring for does not know who they are and, even worse, often will become agitated when the caregiver attempts to assist them. One of the things I have noticed that ADRD caregivers, especially spousal caregivers, often rely on to remain connected is spirituality. I have noticed a pattern over time that spousal ADRD caregivers in our intervention seem to speak and rely more heavily on spirituality as their spouses progress through the stages associated with ADRD. This recognition combined with the tremendous impact spirituality has had in my life the last 7 years resulted in the desire to investigate spirituality in the lives of ADRD spousal caregivers.

During the last 7 years, I have developed a reliance on spirituality to keep me balanced and healthy, emotionally and physically. This reliance is mainly the result of having to cope with my mother being in a coma for 36 days due to a MRSA infection

after a back surgery 3 years ago, a divorce 2 years ago, remaining an active father to my now 4-year-old son, maintaining a full-time job at the VA hospital, and working on writing this dissertation and finishing my classes for my PhD. Needless to say, my reliance on spirituality has grown exponentially over the last 7 years. However, despite my experiences and spiritual growth, I still wonder if I could remain spiritually connected to God and a spouse who had ADRD. This desire to learn how ADRD spousal caregivers apply spirituality despite their devastating circumstances is the quest that drove this study. The end result of this study is that these spousal caregivers have offered some personal themes and experiences for me and for you as the reader to explore and possibly apply to your life.

Participant Selection and Consent

Participants for this study were primarily Caucasian and were recruited from colleagues and friends using “snowball” sampling. Snowball sampling is defined as “a technique for finding research subjects [where] one subject gives the researcher the name of another subject, who in turn provides the name of a third, and so on” (Vogt, 1999, p. 268). This type of sampling is commonly used to recruit difficult-to-contact participants. ADRD spousal caregivers fit this category of participants precisely as they are usually overwhelmed, stressed, isolated, and preoccupied with all the demands of caregiving. To access this hidden population, the researcher asked colleagues, friends, and acquaintances to recommend people they knew who were caring for a spouse diagnosed with ADRD.

Once a name and phone number or email was received, the researcher contacted the participant and informed him or her that he was conducting a study for his dissertation in Marriage and Family therapy at St. Mary’s University and looking for

caregivers of a spouse with ADRD who were willing to take part in a confidential interview as part of this project.

During this initial contact by telephone or email, the researcher also described the study and the estimated time needed to participate. The researcher further explained that to qualify for the study he or she must have been caring for their spouse with ADRD for at least one year. Once this explanation was completed, the researcher asked the participant if he or she had any questions. After all the questions were answered, the participant was asked whether he or she wanted to participate in this study of ADRD spousal caregivers.

If the participant agreed that he or she was interested in participating in the study and if the researcher determined he or she was qualified, a time and location where the participant felt the most comfortable were established for meeting. Locations included the participants' homes and the office of the researcher. At the beginning of the meeting, participants were provided an informed consent to read and sign before they could participate in the study interview (Appendix B). During this time the researcher answered any questions or concerns the participant had regarding the study. During this conversation, the researcher also related that the discussion of spirituality issues related to caregiving for their spouse with ADRD might evoke some strong emotions and may be uncomfortable. The researcher also explained that the interview would be kept confidential within the normal limits of confidentiality. The participant was also made aware that he or she would be asked to review the transcripts for accuracy and offered the opportunity review the analysis of his or her interview.

At this point, if the participant had no further questions he or she was asked to read and sign the consent form (Appendix B) and complete the demographic questionnaire (Appendix C). The researcher was available during this time to answer any questions or clarify anything in the consent form that may have been confusing to the participant. After the participant signed the consent form, the researcher provided him or her with a copy and the participant was asked whether he or she was ready to begin the interview. Only after the participant agreed, did the interview begin.

Data Collection

Data collection involved semi-structured interviews of ADRD spousal caregivers. The researcher conducted all of the 60 to 90 minute interviews. After providing a brief introduction and obtaining consent, the researcher asked the participants to describe how they became caregivers and to summarize their overall experiences. This introduction was followed with more direct questions about spirituality related to the role of caring for a spouse with ADRD. The researcher began this conversation by asking the participant two primary questions: (a) Does spirituality play a role in your life as a caregiver for a spouse with ADRD? And, if so, (b) what is that role? To expand on the information on spirituality provided by the participant, the researcher followed up with open-ended questions such as, "Tell me more," or "Can you please expand on that idea?" To validate the capability of the questions to gather information related to spirituality and spousal caregiving, the researcher conducted and completed a preliminary analysis of the first interview and then carried out a followup interview to review his initial analysis with the participants. Each interview was audiotaped using two high quality 90-minute tapes and separate recorders to reduce potential problems with malfunctioning equipment.

To ensure confidentiality, the researcher labeled each tape with the participant's research number assigned during the recruitment procedure. The researcher transcribed each interview, and then reviewed the transcripts for accuracy against the audiotapes and field notes, making any necessary corrections. Again to ensure confidentiality, the participants' identifying information was deleted from the transcripts and the audiotapes; however, the researcher maintained a list of the participants' names and corresponding numbers. The audiotapes, computer files, field notes, protocols, and transcripts for this project were stored in a confidential, locked file accessible only to the researcher.

The researcher also made field notes during and immediately after the interviews in an attempt to collect all possible data. These notes included descriptions of the participants' facial expressions, posture, gestures, behaviors, and tones of voice during the interviews. To maintain a sense of coherence about this written data, the investigator used a protocol to remind him of the notes he needed to take immediately before and after the interviews (Appendix A). The researcher also kept a journal to record reflections about his own unspoken narrative during and between the interviews.

From these notes and initial impressions, the researcher developed a summary sheet of each participant's responses to the interview questions to compare with his analysis. Since researcher reflection is a key component of analysis in the phenomenological approach, this data served as a systematic resource to unite with the interview data (Moustakas, 1994).

Data Analysis

The first step in data analysis was a reflection on the researcher's own beliefs, assumptions, and biases, and development of a complete description of his own

experience of the phenomenon of spirituality. These data were recorded in a personal journal to which the researcher added reflections before, during, and after the participant interviews. In an attempt to become fully aware of his beliefs and assumptions, the researcher also included in this journal his perceptions of past experiences working with newly diagnosed Alzheimer's patients and their family members in his current job at the Audie L. Murphy Veterans Hospital in San Antonio.

The central data for this study consisted of the interviews. The researcher analyzed these transcripts using the methods modified by Moustakas (1994). The transcripts of the interviews were evaluated by content analysis. This technique refers to the systematic review of transcripts to objectively derive characteristics and themes (Berg, 1998). In addition to the handwritten journals and field notes, the researcher created a computerized method of recording the meaning units, categories, and themes from the analyses of the interview transcripts in document files and tables. The analysis of the transcripts began with a preliminary reading for accuracy, checking for completion against the tapes. During this preliminary reading, the researcher noted any additional reminders about nonverbal communication and emotions that were elicited during the interviews to the handwritten journal notes that he compiled after each meeting with the caregivers. The procedure used for content analysis began with first level coding to create a preliminary list of the caretakers' relevant experiences.

After forming this list, the researcher then analyzed each interview using line-by-line analysis to obtain information about the general caregiving experiences as well as the spiritual caregiving experiences. Line-by-line analysis is a method of analyzing each line of the transcript to highlight each relevant comment. For each interview, the researcher

copied these relevant comments, listing each nonrepetitive statement. These statements or comments became the meaning units of the data (Moustakas, 1994). Meaning units were developed using as much of the participant's own language as possible to capture the idea conveyed in segments of the narrative.

The next step in the analysis clustered the meaning units into categories. The researcher first compiled a list of all the meaning units for each of the interviews, listing any nonrepetitive meaning unit in computerized document files. He then assigned categorical names to these sets of meaning units to describe the impression that he derived from this cluster of ideas or feelings. These categories became the core concepts of the individual participant's experience, and the researcher then reviewed the complete record to assure that these categories were explicit or compatible to the participant's experience.

The researcher then synthesized the categories for the entire sample into several themes. He listed each nonrepetitive category to develop a comprehensive list of all the second level analysis of the data from the interviews. Again, the researcher clustered the categories into groups of similar topics, from which he developed representative thematic statements.

The final step in the analysis was the construction of "a composite textural-structural description of the meanings and essences of the experience" (Moustakas, p. 122). These themes became the foundation for the textural description and included the ideas, stories, thoughts, and feelings that were a composite of the participants' dialogical descriptions.

Quality and Verification Standards

Quality and verification standards in phenomenological inquiry are related to the researcher's interpretation (Creswell, 1998). This interpretation, however, must be trustworthy and credible. Creswell recommended using at least two procedures for quality and verification. In this study, the issue of interpretation is in the phenomenon of spirituality in spousal caregivers of individuals with ADRD. Because phenomenological inquiry is an interpretive and naturalistic approach, assumptions about multiple realities and co-constructed stories become the actual data. The ascribed meaning of spirituality came from both what the participants identified as spiritual and the researcher's own interpretation of the phenomenon in the interviews.

Some traditional means of establishing reliability and validity by searching for consistency in participant responses over time may not be possible, because it is often common for participants to revise their stories from one moment in time to another as they ascribe new meanings to their stories (Sandelowski, 1993). In qualitative inquiry, measures of validity refer to the accuracy of the data gathered and the ongoing interpretation during the data collection process (Winter, 2000). To ensure accurate interpretation of what was being discussed, the researcher summarized each participant's responses periodically during the interviews.

Another procedure, member checks, provides review for quality and verification, but again may lead to problems if participants want information removed from the data. The member checks in this study assured that the interview questions elicited the spiritual phenomenon and substantiated the researcher's interpretations of the participant's responses. Member checks were performed on the first sets of interviews. These

participants were asked to review the researcher's summary of their responses to the interview questions for accuracy, along with any preliminary analysis of their responses with an emphasis on what was interpreted as spiritual phenomenon.

During these meetings, the participants repeated much of the information from the first interview and concurred or disagreed with the interpretations. All participants were invited to review the transcripts. Based upon the responses both during initial and followup interviews and the participants' agreement with the initial analysis during the member checks, the data were only then considered reliable and both descriptive and interpretatively valid. The researcher's own assumptions and biases certainly impacted the process of data collection and analysis, so every attempt was made to clarify his initial assumptions and biases. However, these were clarified through the reflective process of field notes and journal entries.

Summary

The interpretive methodology described above is intended to derive phenomenologically the spiritual aspects of caregiving experiences from participants' interviews. Procedures for informed consent, data collection and analysis, and verification and quality standards were followed closely throughout the research process. The theoretical basis of this project provided for a collaborative, reciprocal experience between the researcher and each participant.

CHAPTER 4

PRESENTATION OF THE DATA

Introduction

The purpose of this study was to investigate spirituality in the caregivers of a spouse suffering with ADRD disease. The researcher interviewed 11 spousal caregivers, 10 wives and 1 husband, over a 2 month period. Each in-depth interview lasted between 1 and 1.5 hours. These interviews were audio recorded and transcribed into 232 single-spaced pages of text. The researcher then analyzed the transcripts for thematic content.

The emerging themes found by the researcher in the analysis of interview material are discussed in this chapter. A pseudonym was assigned to each participant and is used in the following discussion to protect the confidentiality of the participants. Other identifying information has also been removed to protect their privacy.

Participants

Participants in this study consisted of 11 caregivers of spouses diagnosed with Alzheimer's disease or related dementias. Ten of these caregivers were the wives of men suffering from this illness, and one was a husband dealing with his wife's ADRD diagnosis. Table 1 depicts the demographic information in columnar format.

Each participant completed a short 15-question demographic questionnaire (Appendix C). The age of participants ranged from 65 to 86, and, even though all but one participant had at least one adult child, all participants considered themselves the primary caregiver for their spouse. Ten of the participants were Caucasian and one was Hispanic. This created a primarily Caucasian population from which to draw themes. The participants had various religious backgrounds: 4 reported being affiliated with

Table 1

General Demographic Information

PARTICIPANT	AGE	GENDER	ETHNICITY	# OF CHILDREN	HIGHEST LEVEL OF EDUCATION	RELIGION	DIAGNOSIS
Paula	59	Female	Caucasian	2	Graduate Degree School Psychology	Catholic	2006
Nancy	82	Female	Caucasian	3	High School Graduate	Methodist	1996
Denise	80	Female	Caucasian	3	Some College	Catholic	2006
Kristina	65	Female	Caucasian	3	Some College	Baptist	2005
Martha	78	Female	Caucasian	5 2 died	Graduate Degree Nursing/Chaplain	Catholic	2006
Melissa	72	Female	Caucasian	1	College Graduate	Non- denominational	2006
Maggie	76	Female	Caucasian	0	Graduate Degree MBA/Psychology	Not currently attending	2001
Agnes	72	Female	Caucasian	2	College Graduate	Non- denominational	2006
Doris	69	Female	Hispanic	4	Technical/ Vocational School	Catholic	2003
Gail	67	Female	Caucasian	1	Some College	Non- denominational	2002
Barry	86	Male	Caucasian	2	High School Graduate	Baptist	2007

Catholic churches, 3 with interdenominational churches, 2 with Baptist churches, 1 with a Methodist church, and 1 reported not currently attending a church and no affiliation with a particular religion. Educational levels within the participating caregivers varied considerably as well: 2 reported graduating high school, 1 attended a vocational school, 3 had some college, 2 were college graduates, and 3 had post graduate degrees.

Each participant is introduced in this section and the stories of their spiritual history will be described in their own words as much as possible.

Melissa

Melissa is 72 years old and the mother of a 48-year-old son. Her husband began to show symptoms of ADRD in 1997, but he was not diagnosed with Alzheimer's disease until 2006. When asked how difficult she found the caregiving responsibilities on her demographic questionnaire, Melissa responded, "as difficult as I want to make it." She believes that she can choose her own mind set; therefore, she believes she handles her responsibilities very well.

Melissa was raised as a Baptist and continued in that denomination until the age of 21, because it was more convenient to worship with her family. The primary reason her parents raised her Baptist was to teach her

a way to behave, a way to live, a way not to offend God, a way to be nice to people, it was training and how to live. But you weren't worried about going off to heaven. You didn't get saved to go off to heaven; you got saved so you would have God through Jesus to help you be a better person, with God. When you converted you tried to be the best person you could be.

She revealed through discussion that her family's focus growing up was on the rules of religion. The effect of this became clear when she married a man who through emotional reprimands constantly reminded her and reinforced the rules by which a wife should live.

At 21, Melissa moved to Japan due to her husband's military assignment to that country. During this time she became active in an interdenominational church. After returning to San Antonio at the age of 25, she began to attend the Baptist church once again. A few years later, she became disillusioned with religion in general because it taught that God punishes. Being in a marriage where her husband was emotionally abusive, this message did not help her, and she stopped attending. The decision to halt her church attendance was made easier due to the lack of interest in church by her husband and son.

Over the next 40 years, she sought education and spirituality instead of religion. She connected with people of all faiths and implemented the spiritual beliefs that resonated with her and discarded the ones that did not. During this time she bought a piece of property and built a house next to a Buddhist temple. This situation and surroundings resulted in the incorporation of some Eastern beliefs into her life. Today she still defines herself as "spiritual, but not religious," although for the last four years she has been attending Oak Hills Church of Christ. She stated that she

felt at home there because the religious doctrine teaches that God loves us and doesn't punish us and because I get a lot of spiritual support from the members and pastors. They do not judge me. They simply support and care for me.

Over the last four years while attending Oak Hills church and with the help of the Stress-Buster's program at the VA hospital, her spiritual perspective has impacted the way she views her husband's illness. She has come to realize that

my husband developing Alzheimer's is not my fault. It's not my fault and there is nothing I can do about it to change that. The only thing I can do is change me to accept what is and not take on the burdens of the world. And by the grace of God I have been able to do that recently. I can say it, I am God's child. And a good parent wants his children to be happy and a good parent takes care of his children, but only if the children are willing to be obedient. And so I try to be what I think I should be and take care of my husband and I'm not saying be a moral person, I'm saying, you know I try to live what I think is the way I should live. And I think that this is the way that I can say that grace has been bestowed upon me.

The constant search that Melissa has maintained in her spiritual life has continuously impacted her life as a caregiver to her husband. Melissa relies on the grace of God and the guidance that He gives in order to care for her husband and direct her choices and behavior.

Kristina

In 2005 a PET scan diagnosed Kristina's husband with Alzheimer's disease. Her husband's symptoms began in 2002. Kristina is now 65 years old. She has three grown children, two of whom assist her through emotional support from their homes in Austin, Texas. The third of her children has complicated her life to a certain extent by alternating between periods of non-communication and the desire to micro-manage her father's care.

In her initial interview, Kristina described caregiving responsibilities as not very difficult and believes that she handles the responsibilities very well.

Two months after her interview, however, she hit a rough spot due to some rather dramatic events. Kristina visited my office and revealed that one night her husband had tried to attack her with an intent to kill her. When she sought medical help, he was institutionalized for psychiatric evaluation. This period of psychiatric care lasted for three weeks. During that time, many doctors informed her that he had neither Alzheimer's nor dementia, but instead was suffering from major depression that made his behavior appear demented in nature. For this reason, after three weeks, the doctors instructed her to take him back home. Fearing for her safety and feeling that the diagnosis was either incomplete or incorrect, and that he was medicated insufficiently, she sought further consultation with a geriatric psychiatrist outside the institution where he was receiving treatment.

The new psychiatrist diagnosed him with Lewy-body dementia, an ADRD, not Major Depression. Her husband was, therefore, put on different medication, which, according to Kristina, helped to calm him significantly. At the time of the study, Kristina was currently waiting for a neurologist's appointment to confirm the diagnosis and for further recommendations on how to care for her husband.

Throughout Kristina's interview, she kept referring to her religious and spiritual upbringing, which she described in detail at the beginning of her interview. Her words described her religious upbringing best:

as a child, I went to Sunday school and went to church with my mom and dad.

Then as I became a teenager, it was very important and played a very big role.

And at that time, I went to this church that I really enjoyed. And when I was 15, I accepted the Lord as my Savior and felt like I was a child of God. And then I was very active in the church up until my 20s.

At this point in her life, things began to change due to the worldly demands on her time.

I got so busy with all of the kids and all the nonsense that goes on in your life that I kind of pulled away from the church. They always wanted me to do all these leadership roles. And it just got to be so much. I couldn't do as many things there and take care of my family. And so instead of just going to them and saying "Hey, I can't do this much," I was young, and the only way I knew was to get away. I pulled away so I had enough time and energy to take care of my family. When my kids got a little bit older, we got back into church. They were active as teenagers and I was the sponsor on so many different things. And then after they left home, I was just so busy trying to work and take care of myself because I wasn't married at that time and I really wasn't that active in church again.

This fluctuation between activity and inactivity was again punctuated through family demands when she met her soon-to-be husband:

I was very active in church, I had my life together again and church always played a big role. And here again, it seemed like every time I got into church, there were so many things to do and I did enjoy it. It's just now I'd had the time to do it. Since I was single, I could really do the things I enjoyed.

She and her husband decided to become popcorn vendors in order to travel, and, once again, life got in the way of church time. At the same time, her connection to God was not lost:

As we got into that we were traveling so much that we weren't in our church. But even if you're not in church, you still have the lord with you; it's real spiritual. I believe ever since I was 15, I truly accepted the lord as my savior and came to realize He was real and that I wasn't here by myself.

This belief still impacts her today in her role as a caregiver for her husband with Alzheimer's disease. Kristina eloquently stated this by mentioning at the end of her interview that she believes that

the Lord is going to take me through it, I'm right where he wants me to be today. I would like lots of other things. But that's just our mind. Yet, am I where god wants me to be today? Yes! And he'll take me where he wants me tomorrow; everything will be fine.

Although Kristina has not been consistently involved in a church life, her sense of spirituality has not dimmed nor has it faltered throughout her life. This belief that God is with her at all times, and that she is living the life that God would have her live sustains her even in the difficult spots in her life.

Barry

Eighty-six-year-old Barry is the primary caregiver for his wife, who was diagnosed with Alzheimer's disease in 2007. They have two children, now 54 and 62 years old. Barry's wife began showing symptoms in 2005. Barry finds caregiving responsibilities difficult and believes that he doesn't handle them very well.

Barry's religious and spiritual upbringing was affected by an abusive act, influencing him up until recent years. This is his recounting of his journey:

My basic religion, in my early years, was Catholic. And I was raised by my parents to be Christian to be a Catholic. However at the age of 18, a Catholic priest accosted me and he of course asked me to go to confession, which I did. And stupidly I never said it to anybody; I was embarrassed about it, as anybody could be. And when I got into the service, of course I got away from going to church regularly. We didn't have any services, up until the point I was sent to Australia. And got up into the Northern Territory and there was no formalized religious service in the camp I was in. I was just in Australia, waiting for transportation. And I started at that point to drift away from the church.

The hypocrisy of the church began to wear on Barry:

[I] began to think about the "Don't do as I do, do as I say" kind of thing that was going on. In the church I didn't realize abuse was as rampant as it turned out to be and I waited for an answer from the church from God.

For a number of years, Barry did not find the church to be a necessary part of his life since he

was married before I went overseas and I kind of expected that eventually I was going to leave the church. But I never thought I would go back to another religion. Years went by; we were getting along without any religion. We raised our children so that if they decided to have religion, it was up to them. My son married a Catholic girl and my daughter married a Baptist boy. But they did what they wanted to, not as they were forced to do.

In the last few years, he has affiliated himself with the Baptist church, and he has found a spiritual connection with God, which helps him in his role as a caregiver for his wife with Alzheimer's disease. In fact, it was his decision to allow his children to experience the freedom of choice in religion when Barry found himself back in a close walk with God.

My daughter, as devoted as she is, said she wanted us to be in heaven with her and at the time my wife and I didn't think too much about it; we just thought it was never going to happen and we strongly felt that way. ... my wife's background was that she had never been raised in any religion and she had a couple of relatives who were pretty much anti-religion. So they never expected her marriage to last, but it has lasted long enough; we recently celebrated our 65th anniversary with wedding vow renewals in the Baptist Church. This came about by becoming Christians and realizing how friendly, how honestly loving the people were in the church. Finally one day a lady asked us if she could drop by and visit us the following day. And we said, "Sure. We would be glad to have you." When she started to talk to us, she didn't try to force us into it or anything. She just told us what her feelings were and knowing what our daughter's feelings were. She asked us, she read a little from the bible to us. I couldn't even tell you what she read us... We were not doing this because we were afraid we were not going to go to heaven. But we finally realized that we did need some guidance and at that point my wife was still pretty well, she still understood what was going on.

Throughout Barry's recitation of the events that led up to his foundation in the church, the love he feels for his wife, and the effects that these decisions had on her are

very obvious. He was very concerned that the religious decisions he and his wife were making would be difficult for his wife, but Barry said that

there was no doubt in my mind; she had no qualms about saying “yes.” And I thought at first that I would have trouble asking her to go to church. And there is only one time she has said she didn’t want to go to church and that was when we were not feeling well; and I thought it would be best for us to stay home. So even now she has lost most of the memory of what happened; she doesn’t remember our anniversary or the vow renewal, the reasserting ourselves to each other.

Rededicating ourselves to each other, but we did in an atmosphere that made me feel very strongly, that I dedicated my life to Jesus.

Barry’s personal faith walk was largely based in prayer, and its effect on his role as a caregiver and as a person was very clear. He said, “I do pray every evening.” He added:

practically every night and I have tried to watch myself as far as my temper is concerned. And I find it very helpful to me that I can sit back in the evening and communicate with somebody that is able to do something about it. I have come to realize I have no guidance without God and Jesus. As I mentioned, I grew up as a Catholic, but I never knew Jesus. I never thought about “Is there really a Jesus?” It was engraved in my mind that there was and it wasn’t forgotten. But when I finally realized that there is a salvation, that there is a future life where we can be full again and we can be well, we can be together with my family and my wife. And the only thing I can do is to believe it completely. I can’t have any doubts in my mind about it because I’ve had doubts before and I’ve learned so much by

going to the bible study, learning what the bible really teaches us. And everything I have seen so far, convinces me I can live as Jesus wants me, as God wants me.

As Barry has walked with his wife in her struggles with ADRD, he has looked not only at the past, but to the future as well. He expressed his connection to past, present, and future events in a unique way: “And I can’t control what happens in the future, I can’t control Alzheimer’s, so I have surrendered myself to his control, his guidance. That is why I pray every night, almost every night.”

Nancy

Nancy’s story began in a time when the world’s conflict affected her life; one husband lost and another gained. World War II brought her sorrow and joy as well as the first of her children, of which she has three. She is now 82 years old, and her children are now grown with families of their own. Her struggles with her husband of 62 years began in 1984 and continues today, after his 1996 diagnosis of Alzheimer’s disease. Nancy finds caregiving responsibilities as somewhat difficult but believes she handles them well.

Nancy’s religious and spiritual upbringing has had a great effect on both of her marriages. It began with a family that raised Nancy to be focused on church. “We had a very spiritual household when we were growing up. We attended Sunday school. I was baptized in a Methodist church.” Her story continues with a story that seems more like a Hollywood creation of a wartime romance than reality.

When I was married, I was married in the Methodist church. I married a Christian man. We were married just a short time and he went overseas. And after a year and a half, he was, his plane was exploded over Wake Island. They did not have

remains. Consequently, it left me hanging, believing he would actually come home. In the mean time I was living with my mother at the time and it was devastating for us both because I had a two-year-old child. We still kept contact with his family I was just totally mixed up. Living with my mother was a big help because she helped me with my child and also she's a very loving person. Many people call her an angel from heaven. My father died early. My mother had no way of having a living except through my grandfather who provided her with a \$50.00 check every month. There were seven of us at home at that time.

When her future husband entered the picture, he was not coming to court her, but had found her family, with their religious strength, to be the kind of refuge he needed.

The first thing he did when he came back to the states was to go see my family because he just thought my mother was wonderful and I have two younger sisters. And of course he knew I was married, but he thought maybe one of my sisters was available for a date. Well it ended up that he came not long after my husband was killed and we would sit on the front porch and swing. And he would talk to me about his time overseas as well as I would talk to him about my loss. And he loved and still does love little children. And he would take my daughter to the park and swing with her and just play with her; it filled a spot for him and me.

When they got married, Nancy was having a spiritual struggle with herself. Because there was no physical evidence that her first husband had departed from this world, and her religious education had taught her that one woman could not have two husbands, she felt that she failed in her role as a wife.

After a few years, we decided that marriage was the thing for us. So we were married in 1945. And from there our life began. I was not a good wife at first because I felt like I was marrying him in sin, since I did not have something to prove that my first husband was dead. Fortunately, eventually, they uncovered his remains over Wake Island and we had a ceremony to bury the remains of the whole crew in a mass grave. After that, it was just like a big burden of relief for me because up until then I lived believing I was not doing the right thing being married again. But that ceremony and finding his remains just gave me relief in our marriage and now we've been married 60 years.

This romance has had its ups and downs, like every relationship, but throughout all of it, their faith and grounding in God has been a rock and a strong place to stand when things have gotten tough. Nancy described it very well when she explained that “despite my husband’s illness, our ability to share the same spiritual beliefs has helped me to cope with all the demands Alzheimer’s places on me daily.”

Paula

Paula is 59 years old, and at the time of the interview, she had recently sold her home of 30 plus years and moved to a gated community in Austin, Texas. The community was purposely chosen due to its proximity to her two grandchildren, her two children, and to provide safety for her husband who occasionally becomes agitated and wanders due to his illness. Over the past year, Paula has journeyed along the path toward understanding her husband’s illness. After attending a study in November of 2006 at the National Institute of Health (NIH), what was originally diagnosed as dementia has now been more specifically diagnosed as Primary Progressive Aphasia (PPA). This new

diagnosis helped to clear up much of the confusion and stress originating from her attempt to understand the progression of her husband's illness using the insufficient guidelines of Alzheimer's disease or dementia stages.

Although PPA is considered an ADRD and has the usual memory difficulties, it also has some unique features such as the decline in language skills as well as the complication of a more rapid illness progression. Based on this new realization, Paula made the difficult decision to move from a city she had always considered home in order to access more help from her family in caring for her husband. Through this difficult decision, she has become more whole through the blessing of time spent with a grandson and granddaughter who are growing and newly experiencing life at the precise moment when her husband is declining.

Paula returned throughout her interview to the impact that her upbringing and background in spirituality has had and the way that it has helped her through many difficulties throughout her life. This complex role in which she finds herself, caring for her husband with an ADRD, was just another instance in which she has relied on the benefits of spirituality. The way she grew up led her to a monumental decision at the young age of 13 to enter the convent to study to be a nun in the Catholic Church. This was a big decision to make as an eighth grader, but her strength in faith guided her choice. Seven years later, at the age of 20, she decided to leave the convent prior to beginning her life as a nun; however, this experience had a permanent effect on her life. During the interview, Paula highlighted this important time in her life by indicating that "the convent gave me the intellectual side so to speak. But it also gave me a great realization about the fact that God just walks everyday and every step with you." This

ability to walk with God has been a spiritual resource that Paula continues to rely on as she pointed to the idea that

particularly now that I'm approaching my 60th year of life and had been walking this road with my husband for 4 years. I call him an angel. I call everyone that comes into my life, which helps here, helps there; they are angels. I felt like that is what an angel is like. In my mind, I think that's what an angel is. I think angels are people who come into your life, when they need to. And when you get strong and you figure it out, they kind of back out or they may still be in your life. But they don't have to help as much when they first came in because you get it.

Paula's impact on this study was rooted in the fact that she has a high level of knowledge and understanding in an academic sense, but, at the same time, she typifies the daily influence of spirituality in her decisions. This came out in her interview as well as in her bearing and life experiences.

Martha

At 78 years old, Martha has sacrificed and struggled to care for her husband, who has also struggled mightily with his diagnosis of Alzheimer's disease. His symptoms began in 2001. He was not diagnosed until 2006, but their tale began, as so many do, years before the diagnosis was officially made. The events that have taken place since his illness took hold of him have sent them both on an emotional and spiritual roller coaster that ripped them apart and brought them back together. Their five children range in age from 41 to 51. Two have "expired," and the others have taken a passive role in their parents' walk with ADRD.

Martha described caregiving responsibilities as somewhat difficult but believes she handles them well. This was confirmed and supported through the path she has taken over the past 7 years. She is caring for her husband who left her and moved to another state when he started developing symptoms of Alzheimer's disease. Both were in denial at that point. During this time, Martha divorced him and became a chaplain. After being gone four years, he suddenly came back and asked her to take care of him. After much thought and prayer, she decided to acquiesce, and they were remarried in 2006. She became his full-time caregiver at this point and left the role of being a chaplain.

Martha's childhood was unique in that her family structure was not centered around the nuclear family or even a combined family structure. Instead, Martha explained that

When I was 18 months old, my parents, my mother gave me to her mother because she had my brother, maybe 2 years older than I was, and another one was coming along. She had a very impaired heart. In retrospect I saw it as a virus, she had something in childhood to cause a leaking heart. And so, she wasn't in good health, simple to say, she was not in good health. So she gave me to her mother. Her mother, my grandma and grandpa lived on a farm in Hershey, Pennsylvania. A beautiful 200-year-old house, and it was a farm that they didn't do any farming on. Simply I say this because I really remember being separated at 18 months of age. It has taken a toll on my entire life, which, of course, I didn't realize back then. I do know that I yearned to see my mother and my father. And back in those days in the early 30s, during the depression, they probably visited once a month or every six weeks and I know that I was excited when they came.

But again my mother was always busy with the two boys and I didn't ever connect with her that I can recall. And if I gave, that connection was broken when I went to live with my grandparents. My grandma was a saint, but I didn't want to be with her. And so I think I developed a very early, a lonely life.

At the same time, religious ideas and groups surrounded Martha, who related that there were three religious sects there in central Pennsylvania. She detailed, "the Amish, the Mennonite, and the Brethren. They are all plain people and when people see them, they call them all Amish." Because of these surroundings, Martha said that she "had a real religious beginning. My grandfather was Enigmatic in Mennonite Church." Yet for some reason that was never explained to Martha,

they never went to church anymore and there was a lot of bible reading. And I remember my grandmother teaching me all the old hymns because as we did the dishes, we sang hymns together. And that stayed with me. I believed that when I was very young, there was a spiritual connection and I had someone or something outside of myself to hold on to.

Despite the non-traditional upbringing, Martha was taught to have a foundation in God, in an introspective and fellowship way. She described all the hardships and pain she faced in life by calling her life a "life of misadventure, of hardships and of losses," and that all these difficulties

created a place in my being that didn't allow me to do less than to offer to other hurting people. I experienced the tears and the pains of rejection and loss for so many years, that the greatest thing that grew out of it was to understand. You

know how I feel? No you don't understand how I feel. But I could say to myself, "I've been there, I've walked there."

This need in her life, to assist others and provide them with understanding and support, was met perfectly when she became a chaplain. "It was the very best finale to the movie of my life. It was just wonderful. It was the most incredible gift God could have ever given me." Then Martha's life changed once again after deciding to care for her husband at his return:

I resigned my job. And now I am the caregiver of the person I use to give concern and care to. And so I think that even this experience now is another chapter of what it is like to be there for someone when they pass away or when they need you or need something special, because my husband has become a very different person.

Even in her care of her husband, she has seen the need to support and supply herself and him with the very things that her grandmother gave to her as a child. "Yes he has Alzheimer's and yes he is declining rapidly," she said. Martha described her role as a caregiver as

being there for him. He has become a person who depends on me to read to him for the scriptures each day, which I do. And one of the reasons he left me was because of my spirituality and he couldn't cope with that, whatever that meant to him back then. And now he's prepared to be with the Lord. And I don't know how much longer this will go on or cause me to be home before him or not.

Martha knows hardship and burden, but she does not see her responsibilities or her husband as such. She saw this as "the frosting on the cake. Instead of the burden that

we talk about, I feel that God has given me one more privilege.” The privilege is grounded in her ability to look at her life with her husband and her role as not only a wife but also a caregiver, in both body and in spirit.

Maggie

Maggie is 76 years old. Although she does not have the support of children in her role as a caregiver, she relies on her ability to go to God with her need for help. Maggie belongs to a Missouri Synod Lutheran Church. Her husband’s symptoms began in 1995 although he was not diagnosed with Alzheimer’s disease until 2001. She described caregiving responsibilities as very difficult but believes she handles them very well.

Maggie described the role of religion in her childhood as a guide to right and wrong. Maggie's religious beliefs were introduced to her through her father's church life, as well as the surrounding community. Her views of right and wrong, while colored by her religious beliefs, were then reinforced and solidified due to the education system in which she was enrolled. Her perspective was that God gave human beings the brains and conscience to choose their behaviors, which were then taught to her through the schooling that she received:

Well, as a young person, my father was somewhat interested in the Protestant Church because church was just part of everybody’s life in the community. So, I grew up in a small college town and had the advantage of attending a school on the college campus. It had no spirituality in it, but there was strict right and wrong. In other words, there was strict discipline but very understanding discipline. And at the same time, instead of a grade system it was all S’s and U’s. So I didn’t learn what it was like to compete with anyone else until after I got to

high school. I can now see, as a teacher of many years, the advantages and disadvantages of that. So that gave me a proper background. And years later, friends will say: “Well I remember you were never afraid of anything.”

Maggie laughed and continued:

When I think back, well I don't really know why, but I really was never afraid of anything. Because I thought, to me I always had the final reference that God gave us the mentality and brain, and that we have responsibility to just sit up and evaluate situations that came around and make the best decisions we could. And so I didn't always go to the Lord and pray about it because I always figured that He was my God and He was helping me with every decision. This belief still helps me today in my role as a caregiver for my husband with Alzheimer's disease. It calms my thoughts and calms my thinking. It keeps me focused on the thing that is most important above all: caring for my husband instead of worrying about daily details that don't really matter.

While Maggie has a strong understanding of religion, she does not identify herself with a specific church denomination.

Agnes

In 2004, Agnes's husband began to show signs of ADRD, and he was diagnosed with Alzheimer's disease in 2006. She described caregiving responsibilities as not very difficult and believes she handles them well. Her two children, now 47 and 54 years of age, allowed her to make the decisions for the care of her husband, and they have not become actively involved in the process of caring for him. At 72 years old, Agnes is the primary caregiver to her husband and has chosen to look at Alzheimer's in such a way as

to say, “I don’t believe that Alzheimer’s is an evil that has been perpetrated on mankind necessarily. I think it’s a part of the fact that we are human beings.”

Agnes’s father was Catholic and her mother was Protestant. Observing their practices led her to begin questioning religious customs at a very young age. Agnes remembered that

at the age of 10, I actually committed my life to Christ. Then as I got older, I was baptized. And finally when I was 15, I was baptized for the remission of sins in the Church of Christ. I remained part of the Church of Christ until 1999 when I switched to a nondenominational church because I felt like it was the right place for my husband and me. I felt we got more encouragement, the people were more positive and they were doing more things that I felt would be pleasing to God.

Her spirituality assisted her in understanding and coping with her husband suffering from an ADRD:

There are certain laws that govern the fact that we are human and we are going to die. Even the scriptures say: “There’s a time to be born and there is a time to die.”

And so we are going to die of something, even if they find a cure for Alzheimer’s.

Agnes’ ability to look at Alzheimer’s in comparison to other terminal diseases gives a clear understanding of the severity of the disease. While she conceded that

“cancer is a horrible thing,” she continued to say that she finds

dementia is more horrible because you lose the person before they actually die. I know this firsthand because my mother died of cancer and caring for my husband with Alzheimer’s is much more difficult and stressful. But I realize he’s not going to live forever and I’m not going to live forever, regardless of how this plays out.

The spiritual part of her journey as a caregiver is illustrated in her trust that God will give me the strength to do whatever I need to do to take care of him. Knowing that God can handle this even if I can't helps me to get through the difficult times and when I think I just can't go on any longer. My spiritual beliefs also help me because I know that even though my husband's mind is going, he is pretty much gone compared to where he was before Alzheimer's. He was such a great person and now he's just gone as far as I'm concerned. But even though his mind is gone, and he will die according to God's natural laws I believe his spirit will live on. I also believe that God is aware of this progression. So I believe that his body and spirit are still alive and healthy even though his mind is dying. Knowing his spirit is living helps me to care for him although he doesn't always know who I am and can't connect with me occasionally.

Doris

Doris is the 69-year-old mother of four children, ages 37, 42, 46, and 48. Doris's role as a caregiver began in 2000 when her husband's symptoms began, and her role has continued through his 2003 diagnosis to today. Doris said:

We have to suffer in order to earn our place in heaven; I believe that. So that's the journey I'm taking and it's not easy. But you have to humble yourself. God gives us a little bit of happiness and then he humbles us; and I think that's good. I don't ever think I'm better than everybody else and I don't think anybody else is better than me because God does not make mistakes.

In this way, Doris described caregiving responsibilities as somewhat difficult but believes she handles the responsibilities very well. She takes great joy in her

responsibilities toward her husband in his illness, and she bases this joy in the connection that they have with each other and with the church.

Doris was raised in the Catholic Church from an early age, and that part of her family's life continued throughout her upbringing. Doris described this foundation by explaining that

Dad was very strict about going to church, Catholicism. And so every Sunday we go to San Fernando Cathedral. It was horrible because the masses were not in English. But there was a treat to that, if we didn't make a fuss or go with my mom and dad to church, he would always treat us to breakfast. They use to have a little restaurant at the corner; they use to make the best biscuits. So that's where it really all started. I was Catholic. But I remember being taught that as a Catholic I had a duty, to give at least one hour of my time to attend mass on Sunday.

The strength of her sense of duty was reinforced when she married a man who did not have religion as a part of his worldview. She felt the need to teach him about religion. When Doris spoke about her husband, she highlighted this part of their relationship often, describing her husband as

a country boy and he lived far away from the church. So he didn't know what religion was as he was growing up. So when we got married it was so important to me to teach him and have him convert to Catholicism because it was engraved, instilled in my mind that you couldn't live a good life unless you believed in God and followed the Ten Commandments. And so I taught my husband how to pray. Every night he would say Our Father; I would say Hail Mary. But eventually and to this day he still says his prayers.

This connection to Catholicism still connects her and her husband today despite his illness. She sees that he still engages in worship, as displayed in her comment that I still take my husband to church with me as often as I can and he prays; would you believe he follows the mass? And he prays the Our Father, it comes to him, all those prayers come to him even though he can't often remember what just happened. And he sings and it's just amazing. Attending mass is important because I believe as long as I keep in touch with God, He will always be there for me.

Catholicism also provided her an understanding of the difficulties of caring for her husband with Alzheimer's disease. She believes that she has to remember that God suffered for us, and He took all that pain and all the different types of pain. All the people from his apostles, that did not stay loyal to him and all the people beating up on him through all these things. So He suffered for us, he allowed himself to be beaten up; he died for us. And the least I can do is care for my husband despite the suffering Alzheimer's causes him and I. It's a horrible sickness, and it takes your life away. You know I always remember that as we grow older God will provide you with humbling experiences that will allow you to get you into the gates of heaven. In order to get to heaven, you have to hurt; you have to suffer and so my caring for my husband with Alzheimer's is one way I am suffering like Christ in order to earn my place in heaven.

Gail

Gail's family is a combination of distant and difficult, leaving her with little to rely on with the exception of her God. Gail is the mother of one son who is 42 years old

and who does not help with caregiving in any way as they have no communication and have not for years. Gail's husband was married previously and has several children who interfere and are in a constant state of confrontation and hostility toward her with respect to her care of her husband. The children caused her a lot of problems especially at the beginning of his illness. They were in denial of his status as a victim of Alzheimer's disease, and they still struggle with recognizing this fact, despite a diagnosis and behavior that fits this illness.

Gail's husband's symptoms can be traced back to 1999 although it was not until 2002 that he was diagnosed with ADRD. Gail stated that caregiving responsibilities were not very difficult as a rule. She believes she now handles the responsibilities very well although she struggled a lot at the very beginning.

Gail never had the strong family background and support that many take for granted. Instead, Gail has had to find her emotional support in her faith.

"I had a pretty tough upbringing," Gail said, adding that

I think spirituality, or whatever you want to call it, accepting the Lord as my savior helped me survive from a very young age actually. I rededicated my life when I was about 12, but at the young age of 7 I probably accepted Him on my own. This was necessary because my life was pretty tough! There was a lot of drinking with my parents and much of it was very dysfunctional. And so I was very lonesome as a child. I was also pretty scared as a child. But I remember one time lying in my bed at night and I remember saying, "Lord, dear God, why doesn't my mother love me?" And I remember that something came over me and it was like, God spoke to me and told me that He would guide and protect me if I

listen and trust Him. Ever since then I have really believed the Lord has walked with me. I really sincerely believe He was there through all the times when I was left alone with my siblings when I was barely 4 or 5 years old. It was so hard watching them and I was always afraid. But I think spirituality, knowing the Lord and always having that in the back of my mind, even if it was panic in my life or I was afraid of something or I was timid or quiet; just knowing I had Him made everything manageable.

Gail talked about the beginnings of her spiritual life in terms of how she gleaned the information, not from parent figures, but from her grandmother. At the same time, she identified that

He was with my parents from the very beginning. And I didn't know anything about accepting Christ when I was 7. I just remember my grandma talking about the Lord and how He helps her. My grandma was very religious and I just remember little tidbits that she said and if it weren't for that, I don't think I would have survived.

The reliance on God continued outside her childhood, and carried into her relationship with her afflicted husband. The responsibilities and the apparent hopelessness of her situation hit her hard:

When the Alzheimer's hit my husband, I realized I now have all this stuff I have to do to care for him. So at the beginning there was a period of time where I was awful; I resented it and him. I thought, "Why am I doing this?" This man has made no provision for me. I don't know if I will even be able to live in my house after he's gone. And his children don't want to help. I'm taking care of him by

myself and he's awful. And he was awful in the beginning. But I knew caring for him was what I was supposed to do. I know what my responsibilities are as a wife because I've studied the bible and so I told myself, "You know, I have to do this. But how am I going to do it?" And then when his kids began to pounce on me, I was scared because they had so much power and so much money.

The decision to continue in her faith walk has sustained her, as she related. Even though I was scared, I went to church and I made him go with me; sick and all. We went and even though he's Catholic, he didn't want to go, but he went because I told him, "you have to go." And I went every Sunday. I never missed even one Sunday. I knew I had to be in that church and I had to pray. And I had to let God take over because I knew I couldn't do this by myself. I couldn't fight with him and take care of him.

Her walk with her husband has never been easy:

It just overwhelmed me; it was like the avalanche was falling in on me and yet with the Lord's help I still made it. In fact, when I went to the doctor after caring for my husband for a while he said, "My God, you look awful." And he said, "He's going in a nursing home for a few days." And so they kept him in there for two weeks. And when they did, I rested. I didn't know I looked that bad. But I still made it with the help of the Lord. So as far as the spiritual aspect, there's always somebody holding my hand. And there are times like now, where it's pretty dry this is a fairly uneventful time in my life.

Sometimes, the days were harder than others, and sometimes, Gail struggled with her situation. However, Gail continues in her constant reliance on spiritual beliefs today:

I still speak to the Lord everyday. My prayers are kind of different. It's like "Ok, good morning Lord, here I am and guide this day." And sometimes they are not good as others. But there are times where I just sit here at this table and I'll put my hands up and just wait. And maybe I don't have anything to say to the Lord, but maybe He's got something to say to me or maybe He'll simply bring me peace. So my spiritual life is good. At times, I don't think it is good at all, but then again, I know it's better than others because I see the difference. And I know that no matter what happens, I mean if his kids pounce on me and if they take everything I have, I'll stand here in front of everybody and say, "I made it!" Until God's ready to take me home, I'm going to make it and I'm going to be all right. I can't explain to you why, it's just something I know that I know that is because I've been through so much crap.

Gail laughed and said:

I mean there have been people who have been through more than me and I can see that. And I can see being poor and I can see being where I am right now. And it doesn't make any difference. I think it was because I was so poor, that I realized how little money does mean. It just isn't that important, to take it out of here and leave it; it's just not that important. And then look at things that are so strange.

Denise

Denise is an 80-year-old woman with three adopted children ranging in age from 24 to 44. A personal identity developed through both good times and bad. Her husband's symptoms began in 1998, and he was finally diagnosed with dementia almost a decade later in 2007. Her background in spirituality and in personal history has

given her a view of her caregiving responsibilities as somewhat difficult and she handles the responsibilities very well.

Her family history showed a dedication to the church and the intellectual determination to create a personal choice in religious doctrine. Denise described her childhood as being

the oldest of four girls. My dad, until I got out of high school, was an alcoholic. My mother and dad, neither one had, I think my mother had a sixth grade education. My father was a fourth grade. And I was turned onto the church and we lived not too far from Saint Patrick's Church and I admired the people that I knew that were in the church. And I went all the time. My mother and father didn't go because the priest said they were excommunicated because they couldn't afford to send us to Catholic schools, which was a big mistake. But I always had friends that had spiritual backgrounds and I admired that. And I knew many times when I knew for sure that the Lord answered my prayers, I was sure of it. And I was devoted to the blessed mother and Saint Jude. And I read, in fact I read comparative religions. I got into a study, with that just on my own. And I decided that the one I was involved in was the one for me. And I have never been embarrassed talking about my love for the Lord. I know a lot of people are. But I felt such a connection and many things that I thought actually would never happen to me because prayer did happen for me. And my boyfriends were always non-Catholics.

Denise laughed. She knew that eventually she would marry and that her husband would be a Catholic. Denise talked to her priest for a time about entering a convent, but in the end, she decided to simply pray for the right man to come along.

My allegiance was always to my own faith first. Faith is so important and I just wonder how anybody could get through people's lives without having faith. I know I couldn't care for my husband without the faith I have in the Lord, which is why I begin each day by attending church.

Denise explained the personal nature of a spiritual life and its effect on her role as a spousal caregiver by explaining that

Many people say, "You don't have to go to church, I'll just go through, I'll talk to the lord myself." And he said, "Yes, but when you love your parents and your friends, don't you like to be with them? And if it is the house of the Lord, doesn't it give you a special feeling to talk to the Lord?" I feel as close at home as I do at church. But I enjoy going to church, like I do meeting with these people because they're all my friends and there are about 30 of us going in the mornings. But now I've noticed there are a few more going because of the connection with the lord. But I just feel that we better all get on our knees. I can't get on my knees because they need to be replaced! But anyway I just hope and pray that somebody said yesterday, "Don't you think we're near the end of the world?" And I said, "I don't think about that." I leave that up to the Lord. In the same way, I leave my husband's illness to the Lord as much as possible.

Discussions with these participants proved to be rich with information as all had much to say about spirituality and its effect on their lives. All spoke eloquently about

their faith and how it has affected them, both personally and in relation to the care they provide their spouses. All have found a safe place to be, instead of feeling alone or without support.

Emerging Themes

ADRD has changed the lives of all of these participants in drastic ways, yet they hold onto their faith and place their strength in their god. With the daily experience of caregiving for spouses with ADRD, stress, uncertainty, an overwhelming sense of isolation often takes over. People deal with these problems in various ways, but how does their spiritual life impact this aspect of an ADRD caregiver? The emerging themes that came out of the interviews address different facets of spirituality and its effect on spousal caregivers of ADRD victims.

Kristina's description of caring for her husband, who suffered from an aggressive form of dementia, known as Lewy Body disease, highlighted the ups and downs that a caregiver of a spouse with ADRD must face on a daily basis. Her words provide a background against which to examine the themes that are found in the transcripts of these participants. Kristina stated:

The most difficult part about caring for my husband with Alzheimer's is that none of your family or friends, your typical support system, are there for you when you need them the most. They do not get it, they are not there for you, they just don't understand. But you still have God to rely on, guide you and support you. This is important to remember because at the same time you are grieving the loss of your husband, you are faced with trying to raise a child. And while all of this is going on in your life people are standing around looking at you wondering, "Are you

losing your mind? What are you doing? You're crazy, you know?" But if you dare say that I lost my husband, they would go, "What are you talking about? There he is."

So to me, that's the part that needs to be stressed to Alzheimer's caregivers. They need to be helped to realize that they have just had a death in their family and nobody knows it but them. They don't even honestly don't know it at first. I did not know it at first. But I was in such grief, I was so grief stricken and I wasn't dealing with it if it were grief. And I couldn't deal with it; I couldn't get a handle on it because I didn't know what was wrong with me. But I have just had the death of my husband. Plus I had all these extra duties put on top of me to try to swim through it. You have all the financial, the entire medical, and every decision there is to make, all on your own self because friends and family on the outside don't understand or don't agree with what you're doing. So, you have nobody to bounce it off of; you are used to having your husband there to do that. All of it is just gone, I mean its dead, it's gone; it's just as if you died physically. And everybody is laughing and joking. And you are saying "But, what's wrong with you?" That's the part caregivers live with and nobody understands it.

You have physically lost a person, whether it is your mother, your dad, your husband; you have lost them for dead with Alzheimer's. And in turn then you have added responsibilities. That's where you're so overwhelmed, you just want to give up, and think I don't know what to do? And I think everybody in this situation gets frustrated. But if you have the physical strength of the Lord, He will guide you and let you know, "I know you are overwhelmed, but I'll get you

through it. I'll open the doors. Ok, one step at a time and you go forward." But if you don't have the Lord, you don't have anything. You have no one to guide you or give you strength. You might as well be in your own grave that somebody will throw dirt on. So many losses happen daily and you just keep losing more and more, it doesn't stop until they are finally in their grave. And you know when that time comes; I think that every caregiver whether they admit it or not is saying, "Thank God, it's finally here. What a relief!" "I've done it for all these years and I'm grieved out," for a lack of a better way to put it. You think "now I can finish my grieving and it'll end." But you know you grieve somebody a year or two, it's usually different with every individual. But you grieve them and get on with your life.

With Alzheimer's, that doesn't happen, you keep grieving because you lose more and more of that person everyday. And now I've lost my husband, next I'm going to lose my teenager, then I'm going to lose my child, and then I'm going to lose my baby. The loss doesn't stop until they are in the grave. So it's such a long drawn out period of grieving or a constant loss.

And all you can rely on at that point is to believe that the Lord is going to take me through it and somehow believe that He is guiding me and I'm on the path, I'm right where He wants me to be today. You may think is this where I would like to be today? No! You know my mind would say "Hey I would like to be a millionaire. I'd like to be out on a yacht out in the Pacific", you know I would like lots of other things. But that's just our mind, you know it's not there. But in my mind I know this is where God wants me to be today? Yes! And He'll

take me where he wants me tomorrow; everything will be fine because He is guiding me step by step, if I allow Him to.

The themes that emerged from the interview process are shown in Table 2.

Detailed illustrations of each theme are included, and direct quotes from the participants' transcripts supporting these themes and subthemes follow.

Table 2

Emerging Themes

Spirituality and Religion

EMERGING THEMES	
I.	Spirituality versus Religion
	A. One and the same
	B. Separate
II.	Trusting God
III.	Don't Ask Why (because ...)
	A. Acceptance
	B. God's guidance
	C. Prayer life
	D. Blessings
IV.	Growth and Understanding

Spirituality versus Religion

Analogous to the current research literature on spirituality and religion, participants in this study had a variety of views on whether spirituality and religion are independent concepts or part of the same concept. The following section will outline these views.

Spirituality and religion are the same

Two participants, Paula and Nancy, believed spirituality and religion to be similar or integrated concepts. Paula expressed this idea by stating

I see spirituality and religion as the same because I think religion is here to support your life. And if you don't make it a part of everyday, instead of a separate entity, I'm not sure it is functioning to its highest capacity for you as an individual. And so I think I see it all as one, it's all integrated. In other words, both religion and spirituality are meant to support your life.

Nancy expressed a similar idea of not separating spirituality and religion and making it a part of daily life when she stated

I've never thought about the difference between spirituality and religion! To me spirituality and religion are the same because I have had a connection with the Lord all my life, so I believe that He imbedded religion and spirituality in me. I mean my belief in Him and His way has always been there so to me spirituality and religion are the same because I have never separated them in my life.

This idea of not separating spirituality and religion, however, was not shared by the other participants. These participants viewed spirituality and religion as completely separate concepts.

Spirituality and religion are different

The presentation of a religious life and a spiritual life as having a distinct difference was expressed by Kristina, Martha, Melissa, Barry, and Denise. Kristina and Martha explained the difference through their respective aspects of human creation versus personal relationship, while the other three indicated that the difference between

religion and spirituality lies in the external projection of rules onto a life as opposed to the internal expression of devotion.

Kristina offered her idea of how spirituality and religion are different and distinct entities by expressing the opinion that

Religion, I guess the easiest way for me to put this, religion is manmade. Take any of your churches; they are a religion, they have their specific things which they go by, the way that they set it all up, their belief system. But however they choose to hold their service, how they choose to deal with their people, all of those decisions and rules are religion; manmade religion. Now is some of it God guided? Yeah, some is, some is not. But spirituality is what you have between you and the Lord. The spirit is what differs spirituality from religion in my way of thinking. It is the spirit of the Lord and you that have a personal relationship.

When asked about the personal nature of the relationship between God and herself, she answered:

It's very personal. It is a one on one, that is all there is; nobody else is in it. It is your spiritual relationship with the Lord. Religion is the manmade part and, yes, religion is good. Religion can be bad, but yeah, religion is the manmade part. Spirituality is the spirit and you.

She went on to confirm that *spirituality* and *religion* are not synonymous but that she sees that

a lot in just everyday life. But I think religion and spirituality are different because you can't take any one church and say everybody in there is wonderful or everybody in there is terrible. There are wonderful, God loving people in every

church, whether it is Baptist, Catholic, or whatever. I firmly believe that, yes. But I think that spirituality is different because it is between you and God not you and other people. If you have the spirit of God, you'll receive the spirit of God; and you will know you are God's child. It doesn't matter which of these man made religions that you are participate in; religion is just one of the ways you show your love of God by loving others in the church. You help other people; you do God's work. You do God's work through some of these things that religion teaches. But that isn't spirituality; spirituality is different it is strictly the relationship between you and God which is always there regardless of what religion you practice.

Martha stated this difference more simply: "Religion and spirituality are complete opposites. Religion is our effort to connect to God while spirituality is God's connection to us."

Three other participants, Melissa, Denise, and Barry, expressed the idea that spirituality was different from religion. Religion was described as the external representation of a belief whereas spirituality was portrayed as an internal connection or trust in God. For instance, Melissa stated:

Religion is I go to mass every morning and I say three Hail Mary's and two Our Fathers and I and I cross my heart several times, and I pray, or the nun hits you on the knuckles because you did not follow the rules, that's religion. When you hate your brother because he's black, but you always go to church, that's religion. She further asserted that while religion is rules based, spirituality is the

Willingness to accept because when Christ was breaking the rules or laws of the Jewish religion by healing on the Sabbath, that was religion. He was breaking religion not spirituality. What He was doing was a spiritual thing. Breaking rules not to do it on the Sabbath. See I think spirituality is a willingness to accept those things we cannot see. I believe I believe that there is a God and He will take care of me; yet I cannot see tomorrow. I go my merry way and sometimes I just, see what happens. That is the trust in God that is spirituality to me.

Denise and Barry declared ideas that were very similar to those of Melissa. Both participants also described the difference almost identically by describing spirituality as a part of religion. Denise pointed this out:

Well I think the spirituality is part of religion. It is the main part of religion and it's through religion that we get the training I guess from our youth. And some people get it much later in life, especially when there are tragedies like Alzheimer's. It seems like tragedy brings out the spirituality in people, finally deciding that there must be a higher being, a God that we should all honor, trust and who is in control. I also read about other religions and their viewpoint. Some I think are very strange and some are very rewarding actually.

Barry expanded on this idea of spirituality and religion consisting of related parts that when functioning effectively come from inside the person. To express his

understanding of the connection between spirituality and religion Barry mentioned that

Religion is a platform; it's belief. But spirituality to me is much more than just a belief. It's a trust! What I'm thinking of is spirituality is more from the inward, more from your inside. From your heart, maybe from your spirit, but I believe

everyone has a spirit. Sometimes I feel that my spirit and my wife's spirit were drawn into that same place where we met for a reason. But the religion aspect, being Catholic, was just a religion in my life; it did not provide a personal connection to God. It provided a church, a place to go on Sunday. There was a place to go kneel and there was a place to go to, to follow this religion. But since becoming a Baptist and being saved a few years ago, I now believe I am practicing more spirituality than religion when I go to church. I believe that when I see people singing and raising their hands or when our pastor raises his hand to baptize somebody, I believe he's actually talking to God with the words that he says. And asking God to bless these people.

Spirituality to me is an entirely different thing from just saying, "I have religion. I have religion." You have religion, but I had religion when I was a Catholic. I was born as a Catholic. I was baptized as a Catholic. But I did not have the spiritual feeling that I have now when I was a Catholic. I didn't understand the religion. I didn't understand the whole concept. I was told that Jesus died, was nailed to a cross and died, three days later was summoned to heaven. I believed it because I was told it. But now that I have been reading the Bible that I found one which wasn't so big, so I carry it all the time. And I understand so much more about God. And I think it is so much more inside of me now than it was at that time. Religion was never inside of me. But now I realize that spirituality is a big part of religion and both need to come from the inside and involve trusting God with your whole heart and mind.

This ability to view spirituality as “trusting God with your whole heart and mind” played a critical role in the lives of all the participants and led to the discussion of the next theme that emerged from this investigation of spirituality in caregivers of spouses with Alzheimer’s disease.

Trusting God

All participants in this study mentioned the idea that having a trust in God assisted them in caring for their spouse. Three participants, Maggie, Agnes, and Denise, identified the role that trusting God held in their worldviews, and described in depth the influence that this worldview has had on the way they cope with the demands that ADRD puts on their relationship with their spouse.

Maggie connected the trust she has in God with her habit of studying the New Testament and the fact that, through her study of the Bible, she is reminded to trust God daily. Maggie’s interview yielded the following description of this ability to trust God:

I have read the New Testament completely through several times. I don’t worry about things I can’t solve. But, instead, I believe the responsibility you have is to trust God until He helps you to get them solved you know? And I think it this habit of reading the New Testament every night that calms my thoughts and calms my thinking. And it keeps me focused on the thing that is most important above all, which is trusting God. It also takes my thoughts off of the day-to-day requirements, thinking about my husband and all the care he needs, which can be overwhelming and keep me from sleeping. These readings also help me to trust God by reminding me that there is something, there’s something bigger than we are. And that gives me comfort, knowing that God, the Supreme Being is bigger

than we are and everything that happens in life is part of the plan of God, the creator of everything. Knowing that God has a plan for my life help me to trust Him even when dealing with caring for my husband with Alzheimer's.

While Maggie focused on the need to trust God in order to cope with the current situation, Agnes balanced the need to trust in God's role as creator and the knowledge that He is in control with the certainty that He did not create diseases such as Alzheimer's disease. According to Agnes, Alzheimer's disease is simply an outcome of the natural laws God created to allow humans to have choices in their lives. This philosophy was presented clearly in her musings:

Well I have always trusted God. I never gave that much thought; it was just a fact of my life. You know I just believed that God is the creator, that he created the heaven and earth. I never believed in evolution, I believe if God can create the world, He can create it in the snap of his finger. I love the scriptures, you know God said: "In the beginning was the Word and Word was God and the Word was with God and nothing's created without the Word." And the Word, I understood to be Christ. He created all that we know as far as the physical world, and He created human beings and so forth, Adam and Eve. People believe He created evil because He created everything, but I don't believe that He created evil. I believe He created us, He created human beings, and then He gave them a choice. Our choice is what brought evil and death into the world. That was really hard for me to accept but I thought about it for a long time. But I realized if God gave me a choice, He gave other people a choice too. And if they choose to do evil, then God isn't going to come down here and necessarily state their name. This is part

of the natural world, you know. He didn't promise us a rose garden. And to me the fact that God exists is also part of the natural laws that He made and set in motion by giving us a choice. I mean otherwise He would have made us puppets and we would just have been banging on the strings of whatever He commanded us to do.

I don't believe that God comes down here and causes us to be sick with particular things like Alzheimer's disease or, that it's in our genetic makeup. That's part of the natural laws that God put in motion. I mean, God is like the CEO of the world. He has this business plan, this is his plan you know and we don't understand Him, but this is His plan for my husband and I. And He tells us in the Bible, if we believe the Bible, that with Adam and Eve could have lived forever. I mean in our minds, the way I read it they could have lived forever in the garden and there wouldn't have been anything like Alzheimer's disease. God has given us a lot of power in our lives that we often don't think about, but there are still a lot of things that we just don't control, such as Alzheimer's, and we call them part of the natural laws. They're just natural laws that God put in place and they're just part of life. The problem is that especially in the twenty-first century, Modern America, we don't accept these natural laws and God's control of our lives. In the end we need to realize God is in control and just trust Him.

Denise expressed this idea of trusting God with everything by relating an anecdote from her daily life. "It was a time when somebody said, 'Don't you think we're near the end of the world?' And I said, 'I don't think about that. I trust the Lord and I leave that up to Him.'"

This belief of trusting God was mentioned again and again by participants as providing the foundation for how they cope with caring for a spouse with Alzheimer's disease. It is a primary way that they see spirituality as influencing their daily interactions with their spouses. Doris explained:

When I think about how I care for my husband daily, I realize it is all about my spirituality and trusting God. I remember that God suffered for us. And He withstood all that pain, and there were all kinds of pain such as all the people that did not stay loyal to him like his apostles and all the people beating up on Him. So He suffered for us, He allowed himself to be beaten up; He died for us. You know, as we grow older we suffer and get sick with things like Alzheimer's which are humbling experiences to get you into the gates of heaven. You have to hurt; you have to suffer a little like Christ did to get to heaven. So caring for my husband with Alzheimer's is one way I am suffering and being made more humble so I can get into heaven. It is the least I can do considering all that Christ suffered. But when it becomes overwhelming I trust that God will provide for me the strength to endure my suffering.

Nancy actually described a decision she made to trust God when her husband first developed symptoms of Alzheimer's disease and how that decision has helped her over the intervening years. Nancy stated:

Through his bad time at work and my bad time with our marriage, I decided I couldn't take it. I just made up my mind then and that was about 23, 24 years ago. It's such a comforting feeling. I don't worry about it because I can do what I can.

And I do what I think what God has led me to. I simply trust God to lead me to where I need to go in order to best care for my husband.

The observable results of trusting God continue in Kristina's life:

[I am able] to trust God no matter what! Each day I grow in the Lord and that builds the trust. It's just like; say you have a relationship. You and your girlfriend or you and your wife, you do things together and you'll gradually build a trust factor over time. Until you really begin to trust that person. I think it's the same thing with the Lord as were growing through our life. I think that if you allow it, then you can begin to see where God is. He has given you this or helped you through this. Maybe He blessed you with a nice house or a lot of money or maybe it is physical things; maybe it's your health, maybe its just day-to-day helping. But if you give Him the credit for what He's done, then you'll start to see that He's always there for you and that's how that trust builds. Even if it's in a dark hour for you, He's going to be there to take you through it. You're still going to get up tomorrow and you're going to be ok.

The ability to trust God is necessary for Kristina, and it has also affected her life in respect to her husband's deterioration. She has observed a change in her husband's ability to trust God, and this observation has caused her to examine her own faith, forcing her to rely on God and not on herself. Kristina continued her thoughts by saying that

I've noticed lately, it's more difficult for my husband with his lack of understanding and his regression and those memories of a Catholic childhood. It is harder for him to understand things now, and so I do have to be careful because sometimes we can get into a dispute. And I realize it's just him being obstinate

because he doesn't understand and he can't say "I don't understand it, explain it to me." He'll just get more headaches and rebellious. And I just drop it. I'm like "Lord, I know you've gotten it taken care of." I just drop it. "You don't need me to tell him this. Sorry I can't help."

Gail did not express the need to tell God directly that she trusts him as other participants explained, but instead defined her prayer life as a "listening spirit." She related her constant communication with God to be based in her belief

in the Holy Spirit and I have a listening heart. The patience and the listening. I mean if God hadn't given me the patience, I would not still be able to be here caring for my husband. I would run away from all this crap. I would have run away fast. But, I know I'm supposed to be here. I know it! The Bible tells me I married him and I'm supposed to take care of him. Whether I can do it or not has no bearing. The thing is that the Lord will help me, let me do what I need to do by just trusting. And I do trust him. I know very well that no matter what happens, if the Lord is with me, I'm going to be all right. Whatever happens, it's going to happen and there's not going to be a darn thing I can do about it. As long as I do what's right, we're ok.

Although all participants identified the need to place faith and trust in God as part of their spiritual lives, Maggie revealed the feeling of being alone in her faith and thinking that

I may be a little different than most people. I trust God completely. I don't have to have answers, I just tell myself do what God wants, not what I want. I don't think we are meant to know everything so I don't feel the need to ask God why

things happen. After all, how could we know everything? It's not possible right? At one time in my early life I was interested in Philosophy. And in college I took all these Philosophy courses, even in graduate school. And I decided to find out what the sages of the ages really found out about life. After doing all the readings, I decided, "They don't really know, so why am I going to worry about it?" All I have to do is just trust God.

The trust in God extended itself to the belief that there was no need to doubt or second-guess the Lord's decisions. In their experiences as caregivers of ADRD, the participants placed their faith and trust in God over their own struggles. They each have decided that they do not know the whole story, and so, must give the responsibility for the future to God. Therefore, unlike so many in this situation, these participants did not ask, "Why, God?"

Don't Ask God Why

Spouses of ADRD victims often struggle to understand ADRD because of its characteristic of the death of the mind before the death of the body. Many of them wonder why God allows ADRD to destroy the lives of their loved ones. However, the participants interviewed revealed a unique perspective. They did not ask why; they simply trusted in their spiritual beliefs. When reviewing the interviews, four distinct thematic elements revealed themselves with respect to this phenomenon. These thematic elements are the idea that they must "Let Go and let God," the reliance on God's guidance, the consistency of their prayer life, and a lifestyle of thankfulness in the blessings they can identify in their lives.

Acceptance—Let Go and Let God

One of the struggles faced by caregivers was the feeling that they could no longer deal with all the difficulties of their role as well as watching a husband or wife deteriorate before their eyes. It can be overwhelming for many as they encounter a feeling of isolation and weakness that is complicated by the lack of understanding exhibited by family and friends. The way that many of the participants coped with this struggle was to “Let go and let God.” This phrase, and the idea behind it, continued to come up in conversations with the participants. The idea that, as difficult as it was, the caregiver could turn the control of a situation over to God is consistent throughout the interviews.

The knowledge that there was a need to turn loose of the situation and let God take control by not asking why was clearly reflected in Maggie’s interview:

I probably never ask the question “WHY,” unless it’s something I failed to do and I could’ve prevented it. I think we have responsibility to do what we can in life. And what we can’t, we have to accept. And you have to express, let go and let God; and we have to know when that point comes.

When discussing her husband’s diagnosis of ADRD, Doris reflected on her own emotions and difficulties in dealing with a disease that would drastically change her relationship with her husband. She remembered that

I cried when my husband was first diagnosed! At first I was just a basket case. I could withstand heart trouble, diabetes, but Alzheimer’s, gosh, that affects his entire ability to think clearly and to make decisions. This was very difficult to accept at first because my husband used to make all the decisions, and he was just

so strong. But now instead of a husband who can make decisions, I have a young man or a baby that I'm caring for. However, what I have discovered is that if you want to remain sane, you have to accept it and just let go, and let God help you daily.

Paula also struggled with her husband's diagnosis, believing that in order to face it she would need to find a strength she did not believe that she had. At first, she was very overwhelmed, but now, she rests in the knowledge that God is the one in control, even though

When my husband was first diagnosed, the neurologist was very direct. She came in, sat down and told my husband, "You have dementia. I'm not sure what kind of dementia you have, but you have dementia. We are going to find out what type you have and I will give you as much direction as I can, once I know. But this is what you have and life is going to change. You are not going to be able to go back and work anymore at your regular job." When I first heard this I was in shock but by the time we were done talking with the neurologist, I managed to get things under control by looking around the office where I saw people in crutches and children on the floor playing which made me think, "Ok, everybody lives with something and that's ok. You know, why should I be blessed to have a perfect life." No life is perfect. This is our road and we are giving back to God's green earth. So now He's asking some really hard things and you are just going to have to find the strength to figure this all out and make it work.

And that is exactly what I have done for the last 4 years. I've just tried to figure it out. I studied hard to learn about his illness because in the beginning it

was so new. There was no little literature and just every three months, if I had an upset night, I hid the computer after I had done my rosary. I said, “Well maybe tonight is the night you help with Don’s illness.” And for whatever reason, it would balance me out. I might learn a thing or two, between the things of what I have in my folders. But when I went to the NIH [National Institute of Health], I was blessed with people who I have come in contact with. You know, I listen to their stories. And I feel like that’s all I can do. As painful as this situation was, I could just feel the strength of God coming through me. I thought I won’t be broke, this will not take me down. I’m just not going to let it take me down. And I just feel like, life is a mystery to be lived and not a problem to be solved. So, I’m walking the mystery of my life. And who knows, maybe it will be all over in 5 or 6 more years. And then I will just have to see what new place, what new mystery God has for me. But what I know now is I’m in the right place. I know my husband is becoming happier everyday and things are coming together. I honestly believe God will bring it all together for the good if you are open. But I think the challenge is to be open to him. I think I have finally learned through the years to listen and let go. Just let go and let God and he’ll show you.

While Barry did not use the exact phrase in this quote (although he used it in other places), he described the act of letting go and letting God in terms of Job. He also described the strength that God gives to him when he accepts his circumstances and trusts that he does not need to ask why:

After reading about the life of Job in the Bible, I have changed my view of how to care for my wife, I need to have faith and not question God or why this is

happening to her. You see, according to the Bible, Job went through a lot of trials; more trials than I have even gone through. He went through a lot of physical trials as well as losing his money and his holdings and losing his life. But he survived with faith and I'm hoping I can survive with faith. There's nothing I can do about Alzheimer's. Now if I were to complain about it, it's not going to help anymore, it's not going to make anything better. It wouldn't make me feel any better to think about it. I think I would just aggravate myself to go into a worse mental state than I am now. I have to learn to accept it. I'm accepting it as well as I can. Mentally I am, but physically I can't. I don't think I'm a loser. I'm fighting to do as well as I can. I just feel that I'm not doing as well as I should be doing now, and I'm constantly trying to do better.

Gail also talked about giving the situation to God and receiving strength when she felt overwhelmed. She admitted that having ADRD in your life is not easy; however, she has confidence in her belief that

I don't think God will give you anything like Alzheimer's without giving you the strength to get through it. I think the trick is to give it to God. Now that's the hard part because sometimes we'll hold it and we'll try to do it ourselves. In the beginning of my husband's illness, I tried to do it myself. I always do that until finally I just said, "Ok, I quit!" And when I quit, it all comes into line. It all falls into play. And when I look back and I think, "Shoot, He was there all the time. And if it hadn't been for Him protecting me and looking out for me, I wouldn't be here." I know God is guiding me and giving me strength so I simply try daily to

let go and let God deal with the problems that arise due to my husband having Alzheimer's.

Throughout the interviews, participants revealed that they relied on God's strength when they do not have the strength to deal with their surroundings and the responsibilities given to them because of ADRD. This leaning on God is very much a part of spirituality and the resource of God's strength is something that can only be used by someone who has gone beyond religious acts and into faith.

God's Guidance

Because of the unique challenges presented by ADRD and the confusion that surrounds the caregivers of ADRD, there is often a feeling of being lost. Caregivers frequently discuss the fact that they do not know what path to take or how to find the information and resources that they need. The caregivers who participated in this study displayed a very different attitude.

Kristina gave a detailed description of the kinds of guidance that God has provided in her life:

God is always there to guide you and give you signs of where you need to go, but I think when you are very, very stressed and like have this cloud over you. I think things are given to you by God but a lot of times you don't see them because you're so involved in your own world of depression. But if you open up your heart and your mind and just say "Ok, this is what I need, Lord. Guide me and show me what do or tell me what to do"; and, if you mean that, it's not going to be long until you're going to get a direction. It may come from something you hear on TV; it's more likely going to come from somebody you meet face to face.

Or it may come from a letter or an email you've received. Or sometimes you just have this feeling; it's like a compelling feeling that you know this is what you're suppose to do whereas before you were confused wondering what to do. Often I think, "Ok well, I don't know why I know this, but I know this is what I'll do." And I felt like the Lord leading me. I believe He sends the Holy Ghost or the Holy Spirit to be with us. And I believe that's what it this feeling is, if you want to put a name to it.

I have these feelings quite often. One of the most recent times I experienced Holy Spirit's guidance was when I came to the realization that I had lost my husband although he hasn't physically died, because as a Alzheimer's caregiver you experience the death of the person you are caring for long before they actually die. And in my case the particular death I experienced, was the death of my husband. I think this the most difficult things I have experienced as a wife caregiver because the worst thing you will likely face in your life is the death of somebody close to you. You know, I don't know exactly when that realization came to me, but at some point recently, I realized that I have the body of the man standing there, but I do not have a husband. I now have a child. I've lost a husband and gained a child. But I also realized and took comfort in the fact that God is still with me and guiding me. The only negative part is I lost my husband, and I truly had to accept the loss.

Maggie discussed the way she felt that God guided her through this experience by explaining that she also experienced the aspect of grieving even while her husband still lives:

After the initial diagnosis of my husband's Alzheimer's, I would go out and sit on the concrete bench on our front porch and tears would just come. And then after my tears, I would just go back inside and everything would be all right. And so I asked my Pastor about what these tears might mean. I said: "Why am I crying like that?" He said something I will never forget, "God's is guiding you and trying to prepare you for what's coming." And I thought, you know, that's a wonderful way to look at why I am sad. It is God guiding me and helping me to grieve the loss of my husband.

The guidance the God provided in Nancy's life does not deal with grief, but for her role as a support structure for her afflicted husband. Despite the many difficulties placed on them after his diagnosis, Nancy trusted God's plan for them in the remaining time they have together:

My husband was diagnosed with Alzheimer's, and in 1996 or '97 we made the move home. He was a little bit difficult to get along with at first because he had a blow to his ego being asked to retire. He was going to retire, but he was going to wait another year. I did the best I could. I followed what the Lord led me to do and we had a wonderful 10 years, even with his memory problems. And now I feel like we have more time ahead of us because we haven't finished what we started out to do and that's to follow what God had prepared for us. I pray for God's guidance for me to be able to help him through life now that he has Alzheimer's. Because I don't feel like I have to do this. This is something I want to do I want to make his life comfortable as I possibly can as long as I can. In order to get the strength to live this daily, I pray at different times throughout the

day, you know whenever I feel that I or someone else needs God's guidance. I may hear something on the radio and feel like it needs God, or I may feel that something is going wrong with my husband. Just at the time, I simply ask God to guide me through it or to please help that person if they need help, but I'm not obsessed with it.

Barry has sought God's guidance only within the last few years and discussed his explanation of spirituality and its connection to the guidance he has found in his life:

As a child and young man, I had no guidance. I grew up as a Catholic, but I never knew Jesus. I never thought about "Is there really a Jesus?" It was engraved in my mind that there was and it wasn't forgotten. But when I finally realized that there is a salvation, that there is a future life where we can be full again and we can be well, we can be together with my family and my wife. And the only thing I can do is to believe it completely. I can't have any doubts in my mind about it because I've had doubts before and I've learned so much by going to the bible study, learning what the bible really teaches us. And everything I have seen so far, convinces me I can live as Jesus wants me, as God wants me. And I can't control what happens in the future, so I have surrendered myself to His control, His guidance. That is why I pray every night, almost every night. I pray for God's continued guidance in my life. I ask God, Jesus, for guidance and strength to keep me well enough that I can take care of my wife and to teach me how to control myself. How to handle the situation? And I find that after dedicating my life and realizing that I can't control anything. The only thing I can control is to try to control myself and it's up to me to control myself and to be a good Christian.

I also owe it to my wife to treat her as well as I can on the money I make. When I focus on God's guidance, I find everyday that I can find something I can overlook that she did and I find it a lot easier. And of course she still worries me every time she gets up and starts walking around for more than just the reason she's going to hurt herself. I never know where she might end up or what she'll be doing there. But anyway, that's pretty much how spirituality has affected me and how I apply it in my present life, and how I will apply it until I'm taken away. And I hope that I can follow God better by learning more everyday about how to follow His guidance.

Kristina exhibited her need to rely on the guidance that God gives by explaining the reasons she has for not asking "Why?":

I don't ask, "God, why me?" because the Bible tells us that He only wants good for us. And He will take a bad situation and turn it into good. He doesn't give us the bad stuff, but it is still out there. Now is God capable of saying "No, not going to let this happen to you." Yeah, He is. But He does let it happen to us, and it's how we grow, that's how we get our strength. He takes us through each part just one day at a time, hand in hand; give us what we needed at that time to be able to with stand it. Whether it is comfort, whether it's knowledge, whether it's physical people there to help you, He gives you what you need, if you will just let Him. He only wants good for us. So it's not the bad things, it's how you handle them. So, I just don't ask God why situations like my husband developing Alzheimer's happen. Instead, as I get older and weather the storms in life, I notice more and more that other people are going through these storms, too, and that everyone has

their own way and they have to go through them. And some people come out on the other side and they are bitter and hateful, and they are mean and most of them end up in jail or whatever the case you know? I mean you take that bad road. Or you can end up a more loving, caring person that has more of the light of God shining through you. Either way God is always trying to guide you to his path for your life if you will allow Him to. So since God is guiding my life there is no need for me to ask God why things occur.

Prayer Life

There were two major kinds of the prayer life that were brought to the fore during interviews: formal and informal ongoing prayer. In both cases, participants found comfort through the perception of a two-way conversation with God. In many cases, this comfort led to the ability to rest and sleep at night, which is a problem in many caregivers' lives. Participants also consistently discussed an increase in the practice of prayer as they no longer asked "Why," but instead asked for the strength to deal with their responsibilities as caregivers of ADRD patients.

As Gail described the daily responsibilities that her husband's disease has placed on her, she discussed the need for strength and the method through which she obtains that strength. She does not go to the doctor or even a pastor. Instead, she goes directly to God.

My prayer life has been very important in allowing me to care for my husband. I learned in the first three months that I had to take care of him night and day; he was very physically sick and I'm surprised he's lasted this long. He was emotionally sick with Alzheimer's and physically sick as well. So I had to bathe him, clean him, wash him, put him to bed, dress him, feed him, beg him to take

his pills while he was cussing the whole time. The only thing I could get out was in the morning was to pray, "Help me through this day Lord, I don't know if I could get through it and I can't do it without you." And once in a while during the day, when I was so tense, I would say, "Help me God." That all and, "Help me Jesus." Sometimes I would just say, "Jesus, Jesus, Jesus" to myself! But I absolutely will say that I could not care for my husband emotionally and spiritually at the same time without praying or talking to the Lord constantly. It is too exhausting. I just do not have what it takes to do that. So my prayer life is not like a regular prayer. I'll simply talk to the Lord constantly, and I'll say, "Lord, I know I should forgive what my husband is doing at this moment. But I can't do that right now. So hang on to me and help me get through it about without becoming bitter towards him."

I've had the thought that God hasn't answered my prayers and why hasn't He answered them? But there's still that knowledge that I have. That whatever the reason is, it is in his timing and it is in his hands. And there's a better and bigger purpose that I don't see.

Now I study my bible and I read it. I mean it's not like I haven't done that. And I know what the Word says. But there is still that faith I have that goes even beyond the Word because it is something I've had all my life. I don't know how to explain it. There were times lately where I thought this is getting old and I'm getting tired and there are times I feel guilty. But yet I'm very patient and very loving towards my husband regardless. I mean that's not a plus for me, it's the way I am. You know I think it's a plus for the Lord because if he gave me

anything at all in this life, he gave me patience. And sometimes I think, it's probably too much patience.

Paula's proclivity toward a formal church setting, encouraged by her life in the convent as a teenager, translated to her approach to prayer. Instead of the simple, bullet prayers that Gail used to get through her day, Paula had a routine structure to her prayer life, beginning and ending the day with set prayers that influence her mindset for the coming hours:

I am Catholic and I love to go to the one-hour mass and pray to God. I have always called it my shot in the arm for the week. I tried to always garnish something or if I had a hard week at school of teaching kids you know, "Ok God, I'm here to pray and talk about what is happening in my life and you better help me feel better by the time I leave. So that's how I've always integrated prayer into my life. And there's one thing I always say, "Man plans, God disposes." And I added to it, "And we just have to be flexible."

Paula demonstrated the flexibility she feels when she described how she has integrated religion in her life:

Along with going to mass weekly I have also structured my daily life around prayer which is what helps me get through the day regardless of what struggles may occur. I think in some way I have taken my upbringing where I learned all your little prayers and I developed a regiment for myself that helped me work through the day. And normally I try to get up a half-hour before them. And I have this medication I'm suppose to take an hour before breakfast. So I get up, take my pills, start the coffee. A friend of mine gave me a prayer book by Norman Vincent

Peel. Included in this book is one prayer called: *Prayer at the start of the day* where you thank God for the night's rest and you accept his gratitude for bringing you to a new day. And you ask that he, minute by minute, you use the day well. And that he guides you in every problem, everything that happens. So I try without fail to get up and say this prayer every morning. And even though I have memorized it, I open this book and I look at the words because it helps me to focus.

This prayer goes like this: "Dear lord, thank you for the nights rest, which you gave me. I am very grateful for the renewed energy and enthusiasm that it has brought. Accept my gratitude oh lord, for bringing me to the beginning of this new day. I accept it as a precious gift from thee. May I use it minute by minute to do thy will. Guide me in every problem I shall face and every decision I shall make this day. Help me to treat everyone kindly and to be fair, just, and thoughtful in everything today. If I should forget thee during this day, oh lord; please do not forget me. All this I ask in Jesus name. Amen!"

And so I read that little prayer and there's another one I eventually found over the year called: *Prayer for God's power within us*. And it talks about being strong and that nothing can break or defeat us, if we humbly stay in contact with Him. That prayer goes like this: "Heavenly father, help us to know that there is something so great in us, that nothing in this world could break or defeat us if we keep ourselves hungering contact with the lord Jesus Christ. Grant that we may have the greatness of soul to meet each problem intelligently, each difficulty courageously, each crisis gallantly. For this we give thee thanks through Jesus

Christ. Amen!” There’s also a prayer for energy and a prayer about worry. But the starting prayer and this one are my main things. And it’s been very helpful. And those two prayers set my tone for the day. But again this connection with God is what structures my day, it’s the prayers in the morning; it’s the daily comfort for caregivers devotional I have. And you know this is my morning regiment, this is what starts my day.

And at night and I’m going to read you this. This is what cleanses my soul. And if I’ve lost it with my husband, if I said anything that was inappropriate because I just hit the end of my rope, this is what gives me forgiveness every night. I feel I don’t need to go to a priest and say, “Give me absolution” anymore. I have to live with this, day in and day out. And I can’t be running every day to get absolution. I feel that at this point in my life, God is right beside me, and all I can say is, “Please forgive me, I’m doing the best I need to do.” And so at night I say, “Heavenly father, I close this day with thoughts of thee. All day long we watched over loved ones and hopefully me and I pray for... Please forgive the sins I committed today. Do not hold them against me in the mistakes I made. But please give me insight and greater understanding so I will not make the same mistake at all. Forgive me for the things I did not do or should have done and put your stamp of approval on to what you think I did well with. And now Lord I want to go to sleep. Watch over me and give me a good night’s sleep. Give your angels charge over all of us this night and every night, as long as our lives will last.” And that is how I closed my day. And believe it or not I rest!

Melissa, like Paula, has drawn on the structure of a routine prayer to find rest at night:

Every night before I lay down and I go to sleep, I say: “Oh God, I thank you, I’m going to have a good night sleep.” And I go to sleep...I use to have a hard time going to sleep but since I started saying this little prayer I have found myself falling asleep faster and sleeping better.

The strength that Barry asked for was often the desire for patience and strength, but it was also the desire to include God in the decision by praying.

If I feel that I’m going to need some strength during the day then I’ll pray to God to “Let me have the strength to do what I need to do” without blowing my top. I got to learn to regulate my excitement, my anger; especially when we’re alone and I feel that she’s doing something I don’t want her to do. Maybe I don’t want her to do it, but maybe I should let her. Let her do what she needs but not stress. I realize it doesn’t do any good to get excited about it and I try not to get excited. I think I’ve been controlling myself. So, I find now there are things I’ll overlook because they didn’t matter anyway. She is slowly not remembering instances and I used to let that bother me. Now she takes the towel and wipes herself when she’s off the toilet. Takes the toilet paper and rubs it against her eyes, it doesn’t matter, that can get washed. I don’t like it, but she does it. But she can’t help it and I can’t control it, to tell her not to do it cause she doesn’t understand. So at times like this I pray to God for patience and strength

Gail summarized this practice of prayer by explaining that

I pray for my husband constantly but what I pray for is a little different. I don't ask God why this occurred with my husband or pray for a cure on a regular basis because I don't see it. I don't see it. I don't know why this happened to him, but I pray for a window. I pray for a window. I think with all the diagnoses, it's not going to change. But I pray for a window where he might accept Christ, I pray for that window. If there would be a window there because I don't know if he has and that bothers me. And I pray for at least a window. And I tell him if you can't do anything else, if you could just give him a window where he would realize who you are and he needed you to come into his heart. You know, I pray for that and I pray for that a lot.

Blessings

Throughout the stresses and apparent burdens of caregivers' duties and responsibilities, participants indicated a refusal to look at their lives as incontrovertibly stressful or burdened. Instead, they took the optimistic view that they had been given blessings and the ability to be thankful. The participants reflected on everything good in their lives and the blessings that they have which assist them in caring for the man or woman that they love. Paula illustrated this view by stating

I don't ask God why and I don't feel sorry for myself because I sit and I watch things on television. And I think about that mother who had her 19-month-old, who had a terrible illness and died. From the day the child was born she was not able to move? She was only 19 months and she had to live through that. And after she died, the mother has to go on with her life without her. And this is a not apple

to oranges. You know I am blessed in a sense because I had 30 good years with my husband.

Even at the outset, at the very diagnosis of ADRD, the decision was made either to ask God “why” or to let Him take control of the situation and no longer ask “why.” The decision to accept the circumstance, lean on God’s guidance in their lives, rest in their prayer life, and view their life through the veil of blessings, changed these caregivers’ worldviews. The decision to accept ADRD and the disease’s role in their lives may not have come instantaneously, but it positively affected each and every one of them.

Gail pointed this out in her own experience, explaining that after the diagnosis of Alzheimer’s

I was really mad because my husband was sick. I mean I was really mad because I thought, “This isn’t fair.” I found myself asking, “Why me? I mean enough is enough in my life!” and then I got to thinking about Christ. And I thought, “You know, He carried all our sins.” And I thought, “What a burden!” I mean I really sympathized with that, an unbearable burden that Christ carried. Then I felt guilty because I can’t even do this, I’m mad at my husband having Alzheimer’s, so you know through a lot of prayer and talking to Christ I settled it within my heart, within my soul. After that, I never asked God why again, I simply talked with Him whenever I needed strength or help. So, when I don’t understand why this or that is happening to my husband and me, I think there are a lot of things I don’t understand. But I know there’s a purpose behind it. I believe that Jesus understands them. I know I won’t understand anything, ever, ever. But there are a

lot of things I would like to ask Jesus if I get to heaven. I would like to ask, “WHY?” My nature is, “WHY?” But I don’t get hung up on waiting for an answer because that would make me miserable and I know there are some things I am not suppose to understand.

Martha’s focus on blessings was revealed in the idea that she had seen the circumstances that surround many others in her community, and so she often compared the difficulties she has observed with her own obstacles, expounding that

the sum total of my experiences in life, especially in the last 5 years as a chaplain, of going into homes that don’t even have air conditioning and seeing people die alone is that I now realize the incredible gifts that I have. I have plenty to eat, a beautiful little home, and my husband and I still have each other even though he has this illness. I have come to realize that everything God has made is so incredibly good. And I ask myself why am I so blessed? Why am I so blessed with all these items and opportunities. I guess even though Amazing Grace is sometimes so over done, it fits my life perfectly because it is true that “Once I was blind and now I can see.” I see all the beauty of God now. I see all the blessings and all the graces and the gifts.

In looking at her life, Melissa found the many aspects of her own life that assist her in her care of her husband, and she gave God credit for minimizing the difficulties that bad health would give her. The blessing in her life to which she pointed was that of grace:

Even though I get stressed at times due to all the demands that go along with caring for my husband, I never stay that way for long because I will remember all

that I have to thank God for everyday. I'm thankful that I'm 73 years old and I can work like a horse, I have all my teeth and except for not being able to see up close, I have good eyesight. I also thank God that I have a good bed and I have a good house and the house is full of fruit and food and I can eat light food, and eat them as I go along. This biggest thing I thank God for each day is His grace, which provides me to be at peace no matter what occurs throughout the day. I often think and say only "by the grace God has given me, can I have the peace that passes understanding." How else could I have such peace in midst of this terrible hour of caring for my husband with Alzheimer's disease?

Barry took a direct approach to cataloging those aspects of his health and prosperity, which allowed him to be a caregiver:

Despite my wife having Alzheimer's, there are still many blessings that God has given me. One of the biggest is that God has kept me healthy so I can care for my wife. I believe I'm as healthy as I can be, for being 87. I can still walk, I can still drive, I can still see. Even though I'm having problems with my eyesight, I got double vision. But I feel that God is keeping me around to take care of her. She spent her life taking care of our family, taking care of me, taking care of all my needs. I feel it is retaliation; I get to give back to her for doing all these things. In fact, I've learned as much from her and I want to be there to do it. So staying healthy is definitely a blessing God has given me.

Paula had a unique method for enumerating her blessings so that she had a tangible result to look at and hold:

I have a quilt that I made for our 30th anniversary, and that quilt brought into perspective the blessings God has given me after my husband was diagnosed. I thought, “There is my gift.” I got 30 years of a wonderful marriage and many more to come. That is 30 years of raising children. I had a marriage; I have a man who loves me. And we had good times together, and we traveled when we could and camped with the kids, you know? Unfortunately with his job, we would go to the coast every summer and used their condo. I mean we were lucky. And even though, obviously, I’ve walked the road of heartache with the family, as we all do, all these 30 years. But I thought, “I was blessed. So the last 10 years were a roller coaster, well ok, we’ll ride the roller coaster. You know, that’s what God is asking.” And He’s not asking me to do it without support. And anytime that I get really scared, I will sit down and just have a conversation with God. And I have sit and I have sit.

Like Barry, Kristina looked at the positive results that her husband’s diagnosis had in her own life. She also acknowledged that

God is so good to us. Sometimes we’re our own worst enemy; we just won’t let Him give us the blessings He wants to give us. For instance, becoming a caregiver for my husband has, it made me reevaluate my own personal self and it made me reevaluate what was important to me now. This ability to reexamine my life is truly a blessing God has given me during this time.

Doris expanded the view of blessings not only to her emotional and physical health, but to the financial health she had been given:

Yes, there are many blessings even in the midst of my husband developing Alzheimer's. We have four wonderful kids, number one, and we have 13 grandchildren. We also are able to get together and enjoy Christmas, Thanksgiving, and other holidays and birthdays. It's just a wonderful blessing to be surrounded by all our kids. Another blessing is we don't really have bills so I have options should I need help or to place him in a assisted living in the future. This is a huge blessing God has provided my husband and I.

Growth and Understanding

The ultimate role that spirituality played in the caregiver's eyes was the ability to see past the obstacles and keep them out of the traps and pitfalls in which many caregivers find themselves, such as fear, depression, and isolation. Participants in this study saw each difficulty that they encountered as an opportunity to grow in their spiritual faith and to find a greater understanding of the plan that God had made for them.

Kristina fully admitted that her trust in God and her spiritual life were not perfect, as there was still much room for improvement, growth, and understanding:

There are still occasional times when I spend time in fear and going Why me. Everybody in life is going to have something to fear. You know life isn't just a bowl of cherries all the way through it. So everybody is going to have enjoyable times, they are going to have sad times, and they are going to have difficult times; that's the way life is, so how do you handle them? That's what's important. That is the growth factor, and that's where I believe with that Lord, you are able to grow whether it is a healthy matter or you're going to be a better person. You're

beginning to understand more about life and understand more about God's love.

And you'll understand more now about God's love, for all the people in general.

While Kristina looked to future spiritual growth, Melissa concentrated on how far she felt that she had come since the beginning of her trials with her husband's AD/DR:

I have grown spiritually as a result of caring for my husband with Alzheimer's.

The spirit has taken from me the agony of failure. The grace of God has lifted from me, the burden of self-incrimination, you gotta do this, I now know I don't gotta do it. This growth was possible because I have come to believe that grace is kind of this loving protection. Often in my life grace has been some message to be willing to accept these gifts that God provides. I can say it now, I am God's child. And just a good parent wants his children to be happy and a good parent takes care of his children, God takes care of me but only if the children are willing to be obedient. And so I try to be what I think I should be and what God wants me to be. So I do the best I can to take care of my husband daily. I try to live what I think is the way I should live according to God's plan for my life. And I think that this is the way that I can say that grace has been bestowed upon me. "By the grace of God," although I have been through agony, I had been set free and I know that sounds hokey. But there is no other way to explain it because with my husband the rule maker gone, I would be wallowing, unable to do anything because I don't know what to do without the rules. I don't have the rules that I had, but I'm still perfectly happy. That's the grace of God.

The life that Martha has led and her experiences as a chaplain gave her a framework through which to grow in understanding with the Lord. While many people

would crumble under the experiences she has undergone, she has taken them and applied them to helping others through their own situations. There is no better example of growth than someone who can take their own problems, live through them, and assist others in their process of growth through trials and tribulations in their lives.

The death of my mother, the death of two sons, the loss of a husband, all of these things have created in me the experiential link to the Lord. So each incident of hurt and loss created a new understanding for something I never had before. It was like affliction was always a blessing in disguise because it catapulted me into a new understanding and a new compassion.

The long and short of this whole story is that my life of misadventure, of hardships and of losses, created a place in my being that didn't allow me to do less than to offer to other hurting people. I experienced the tears and the pains of rejection and loss for so many years, that the greatest thing that grew out of it was to understand. "You know how I feel? No you don't understand how I feel." But I could say to myself, "I've been there, I've walked there." And so when I became a Chaplain, it was the best. It was the most incredible gift God could have ever given me.

Conclusion

Through discussion with these participants, certain elements of the stories traversed their different backgrounds, religious preferences, demographics, and individual situations. As the participants spoke, the themes, such as their views of spirituality and religion, trusting God, not asking why the illness occurred, and growth and understanding, continued to appear. Despite the dramatic tales that peppered the

interviews, the strength of the participants' faith and spirituality was intense and vibrant. The way that the participants have relied on their spiritual beliefs throughout their difficult relationships as caregivers is evident in the stories they tell in their own words of their positive worldviews and of the love they hold for their spouses who, due to ADRD, are no longer the same persons they once were.

CHAPTER 5

SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

Summary

Whether the drastic increase in ADRD cases can be identified and credited to the improvement in diagnosis or to an increase in the actual number of people suffering from these diseases, the fact remains that by 2050 the number of diagnosed cases of ADRD is expected to double from 4.5 million Americans to 8.7 million unless a cure is found (Brookmeyer et al., 1998). The results forecast substantial financial and social burdens for both the patient and the informal family caregivers (Langa et al., 2001).

As the spousal caregivers focus on providing care to their husbands or wives, they lose track of the risks and costs associated with being caregivers (Mittleman et al., 2004). Caregivers of spouses with ADRD have been shown to have higher rates of depression, reduced life satisfaction, and increased physical health problems when compared with noncaregivers (Pinquart & Sörensen, 2003; Roth et al., 2001; Schulz et al., 1995). Not only do spousal caregivers experience the difficulties that the role of primary caregiver brings, but they must also deal with the changing marital relationship that the progression of the disease involves (Stoller & Cutler, 1992). Consequently, the caregiver's health is negatively affected.

Research shows that “elderly spouses strained by caregiving are 63% more likely to die during a given 4-year period than other spouses their age” (U. S. Department of Health and Human Services, 2002, p. 2). Due to this fact, mental health professionals have been seeking ways to assist these caregivers and to improve their lives. Research has included stress management, coping techniques, and, recently, the benefits of spiritual practices (Kaye & Robinson, 1994; Stuckey, 2001).

Throughout the research dedicated to the subject of caregivers, very little close attention has been given to spirituality and its effects on the caregiver. With the recent climate change in the counseling community toward acceptance of spirituality, more researchers have addressed this subject (Miller, 1999; Miller & Delaney, 2004; Richard & Bergin, 2000; Shafranske, 1996; Sperry & Shafranske, 2004). There is, however, a gap in the research due to the quantitative focus of the journals in which the research has been published. A qualitative approach is needed to investigate the effects that practices and beliefs of a spiritual nature have on the caregiving experience of ADRD caregivers.

The researcher took a phenomenological approach to research the subject of spirituality and the caregivers of ADRD victims through a series of open-ended interviews. Through this approach, caregivers participated in 60- to 90-minute interviews, providing as much or as little information as they were comfortable in sharing. Eleven individuals, 10 wives and 1 husband of ADRD patients, participated in this study.

From these interviews, four general themes emerged. Within these themes, six subthemes came to light. The four themes were *Spirituality versus Religion*, *Trusting God*, *Don't Ask Why*, and *Growth and Understanding*.

Within *Spirituality versus Religion*, two divergent subthemes were identified due to the individuals' definitions of spirituality and religion. Two participants believed that the two were "one and the same," while five saw a difference and a separation between spirituality and religion. The difference is shown in the idea that religion is a manmade construction defined by ritual and action, while spirituality is a deeper connection and

relationship with God. Both opinions were well supported; however, the majority of participants expressed the opinion that they were separate.

When discussing the trust that caregivers had in God, there was a consensus among them that trusting in God did assist them in their caregiving responsibilities. The frame within which many participants described *Trusting God* began in their individual religious backgrounds and the description of how that worldview influenced their current duties and mindset. Each participant had a unique story to tell, and yet, in the end, they found peace and strength through the trust that they placed in God.

Within the theme of *Don't Ask Why*, four interconnected but still distinct subthemes were uncovered. These subthemes were God's guidance, prayer life, acceptance or "Let Go and Let God," and blessings. The caregivers decided, at different times and through different kinds of experiences, that they did not have all the answers, but at the same time, they did not need to ask "Why?" During the interviews, the participants clearly defined four major reasons for not asking God why He allowed ADRD to affect the lives of their loved ones.

The first subtheme uncovered through the interviews was the participants' belief in the presence of God's guidance through the difficulties and confusion that surrounded caregivers of an ADRD patient. When the participating caregivers did not know which decisions to make, they simply rested the decision in God's hands and did not ask why, but asked for the guidance and wisdom to make the best decision possible. Caregivers felt that if they needed something, or were unsure of their situation and choices, all they had to do was to seek God's guidance in their daily lives.

The prayer life of the caregivers was another source of strength and peace in their lives, because as they asked God for whatever they needed, they had the belief that when they entered into a prayer conversation with God their prayers would be answered. The participants said that prayer had become a significant part of their daily routines since ADRD has entered their lives. They noted a change in the tone of the prayers from one of “Why?” to a request for strength. Overall, two types of prayer lives were described. Some participants relied on formal prayers and structured prayer time. Others were not so formal, but continued to pray throughout the day whenever they felt the need to connect with God.

While the role of a spousal caregiver to an ADRD victim can get overwhelming with feelings of isolation and weakness, the caregivers accepted that they had to turn over the situation to God, and they consistently acknowledged in the interviews that they did have the ability to “Let go and let God.” It was also apparent in the discussions recorded in this study that the participants relied on God’s strength when they did not feel able to cope alone.

Despite the stress and easily discerned duties of the caregiver’s daily life, the fourth subtheme that emerged from the interviews was the focus, not on the negative effects on the caregiving experience, but on the positive blessings that they could see despite their situation. The participants found reasons for rejoicing as they looked for ways that their lives are good instead of seeing only the bad things that their situations had made for them. Because their thoughts were on the blessings that they had, they did not ask “Why?”

The impact that spirituality has on the caregiving experience is found in the participants' view of the future *Growth and Understanding* that they can still obtain in their relationships with God. The participants did not claim to have a perfect spiritual life, but they knew they could continue growing in their personal relationships with God. The ability to look back and see the obstacles that they had endured and to look forward beyond the problems that lie in their path is easily apparent in their sense of spirituality.

Although this sense of spirituality helped the ADRD spousal caregivers in this study, more research is encouraged due to limitations found in this study's methodology and participants.

Implications and Recommendations

One supposition the researcher brought to the study was that spirituality could be important to caregivers of a spouse with ADRD, because many authors have discussed that spirituality is an integral and necessary part of the human experience (Eliade, 1957; Frankl, 1984; Hardy, 1979; Maslow, 1968/1999). However, the participants' strong assertions that spirituality is vital to caring for a spouse with ADRD are not explicit within much of the literature about spirituality. The implication that spirituality can assist ADRD spousal caregivers provides important information to marriage and family therapists who are working with people who find themselves in this role. The findings of this study suggest that, at least for the caregivers in this study, spiritual beliefs can provide a healthy bond to God and to the spouse with ADRD.

If spirituality can be so important that it alters the perception and daily experience of caring for a spouse with ADRD, then perhaps marriage and family therapists should broach the topic of spirituality with their clients or refer their clients to others able to

discuss this important area. Spirituality can provide hope and reassurance to caregivers who are engulfed in the stress and despair often associated with ADRD caregiving.

The study suggests that spirituality allowed these participants to find meaning in being a spousal ADRD caregiver, and, in turn, the new sense of purpose provided a reason to continue in the role despite the stress and demands of ADRD. Therefore, at least for these caregivers, spirituality was shown to be vitally important in finding a connection to their spouses and to their own identities while caring for a spouse with ADRD.

The findings of this study help to articulate the relationship between simply existing and being active and how these concepts may be integrated in individual, marital, and family therapy. The discussion of the difference between a sense of self and action are both important to marriage and family therapy; however, their relationship to each other is not well understood. The finding of spirituality as a sense of being that enables doing also provides marriage and family therapists with a way of discussing and facilitating being dimensions of caregiving in therapy. That is, it suggests that to facilitate clients' involvement in meaningful doing, we need to help them to connect first to their sense of their spiritual selves.

Spirituality helped these participants cope with living with a spouse with ADRD, because participants' spirituality gives them guidance, meaning in life, connection to others, and assistance in doing. These participants' sense of spirituality also provides for them a role in life that is not part of the 'sick role.' Participants were able to describe themselves as spiritual beings rather than solely as people caring for a spouse with ADRD. The fact that they are caring for a spouse with ADRD is a secondary rather than a

primary daily consideration. Thus, in this study, the participants' sense of self is not defined as persons who are caring for a spouse who is dying but as spiritual beings living a spiritually rich life. There is evidence that authors support the finding of the present study that spirituality can help a person cope with caring for a spouse with ADRD. For example, Stolley (1999) found that ADRD caregivers ($N = 64$) used prayer and religious coping frequently, that they perceived prayer and trusting in God as effective coping mechanisms, and that internal religious activities helped them get through the caregiving situation.

The fact that spirituality was perceived by participants to be life-sustaining and life-enhancing has important implications for the field of marriage and family therapy. In the present study, spirituality was found to be a valuable dimension of caregiving as it helped participants to cope with living with a spouse with progressive illness like ADRD. In addition, it provided meaning in life that precluded getting caught up in stressful and depressive thoughts such as asking "why me." Clearly, spirituality's relation to marriage and family therapy remains underresearched. However, despite this challenge, it seems that spirituality is a dimension of life that is vitally important for some spousal caregivers and definitely part of their caregiving engagement. As such, it cannot and should not be ignored.

To address the spiritual dimensions of clients better, marriage and family therapists may need to take a number of different actions. First, therapists must accept and be willing to discuss spirituality with clients during therapy. To develop more confidence in their understanding of the spiritual aspects of caregiving, marriage and family therapists should explore and conduct further research. They can decide to educate

themselves more explicitly about spirituality in the marital relationship when it is impacted by ADRD. Additional research in this area is clearly needed to change attitudes, professional education, and practices to ensure that we discuss, and are equipped to deal with, the spiritual dimension of progressive illnesses such as ADRD.

While this study provided an excellent opportunity to learn about spirituality and its relationship to caregiving and marriage and family therapy, it does not cover all that can be known about this complex and diversely experienced phenomenon. Because spirituality is a topic that is by its nature intangible and very difficult to study, more research is needed. This research may provide beginning understandings that further study can extrapolate.

First, since this study focused on primarily Caucasian participants, studies need to be conducted with a more racially and culturally diverse sample. The sample could include participants with various experiences and backgrounds, including religious beliefs, cultural influences, income levels, or inhabitants of differing regions of the country. These future studies are necessary because all families are not all Caucasian and the emphasis on caregiving may not be as isolating an experience across cultures. This will provide researchers with a more varied understanding of the effects of spirituality in diverse populations.

Second, since access to spirituality can be achieved only indirectly and only as it is filtered through the researcher's and the participants' experiences, other researchers may form further opinions and conclusions from the same data set. As stated above, further research would benefit this subject. It would be useful to conduct more

phenomenological research with a larger cohort of people and to understand the full scope of spiritual experience better.

Third, having discovered that spirituality can imbue everyday caregiving for a spouse with ADRD with meaning and purpose, more detail about how people connect to and experience their spirituality in daily life could be examined.

Finally, other investigators may also be able to offer alternate understandings given the different assumptions and experiences they would bring to the research in addition to those of their participants. Researchers may expand the general understanding of spirituality's influence through their own individual experiences.

Conclusion

The present study shows that spirituality can give caregivers of spouses with ADRD a reason to continue day after day, rather than to become stressed or depressed. Spirituality was essential for these participants as they searched for their own individual purpose and identity. The result of their strong spiritual life enabled them to be more efficient and effective in their daily activities. The experience of being spiritual for these participants led to meaningful caregiving, reinforced their spiritual beliefs of connection to themselves, to others, and to God, and instilled their lives with meaning and purpose. Ultimately, the participants' worldviews set up a cycle of life-sustaining beliefs. Marriage and family therapists who are interested in assisting ADRD spousal caregivers regain health and experience well-being may be interested in the idea that life-saving and life-enhancing spirituality can be expressed and facilitated through interviewing.

This research indicates that marriage and family therapists can affect the development of meaning and purpose in life through conversation, and it provides an

impetus for them to learn more about the relationship between spirituality and caring for a spouse with a progressive illness such as ADRD. It also provides motivation for researchers and marriage and family therapists to learn about spirituality at both undergraduate and continuing professional development levels, so that they can ensure that they attend to spiritual dimensions within their therapy practices. While not all the answers have yet been found, it seems that spirituality can be conceptualized as a treasure that marriage and family therapists can help spousal caregivers to discover to assist them in living more meaningful and satisfying lives.

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Appendix A

Data Management Protocol Form

Interview Protocol*

Project: An Investigation of Spirituality in Alzheimer's Disease Spousal Caregivers

Time of Interview:

Date:

Place:

Interviewee Code:

Participant's questions

Notes about facial expressions, behaviors, gestures, tone of voice, eye contact, posture:

Post interview:

Emotional response (comfort, discomfort)

Most important information related:

*Adapted from Creswell (1998) p. 129

Appendix B
Informed Consent Form

St. Mary's University

**CONSENT BY PARTICIPANT FOR PARTICIPATION
IN A RESEARCH PROJECT**

Title: An Investigation of Spirituality in Alzheimer's Disease
Spousal Caregivers

Principal Researcher: D. Allen Novian Jr. Doctoral Student in Marriage & Family Therapy
allen_novian@hotmail.com; (210) 414-2283

Faculty Sponsor: Randall Lyle, Ph.D.; rlyle@stmarytx.edu; (210) 436-3226

I am being invited to participate in the above mentioned project. My participation in this study is entirely voluntary, and I may refuse to participate or decide to cease participation once begun. I may discontinue my participation at any time without any consequences, further obligations, or notice.

I am being asked to read the consent form carefully. I have been informed that I will be given a copy of this consent form to keep, if I decide to participate in this study. During my conversation with Allen, I was told that the purpose of this research is to investigate with the principal researcher the experience of spirituality in my life as a caregiver for a spouse with Alzheimer's disease. I was also informed that my contribution to this research will be combined with the efforts of other caregivers of a spouse with Alzheimer's disease to examine any potential themes of spirituality that may become apparent through this research.

I was informed of the following research procedures, and I am committing to participate fully, cooperatively, and collaboratively with the principal researcher by giving my best efforts to complete the following responsibilities as co-researchers:

- 1) I will participate in a 60-90 minute interview with Allen Novian. This interview will be audio-taped using two tape recorders in order to provide a backup copy in case one malfunctions during the interview. During this interview, I will be asked about my experience of spirituality in my role as a caregiver for a spouse with Alzheimer's disease.
- 2) After the interview the tapes will be transcribed by Allen. Once my recordings have been transcribed using pseudonyms the audio recordings will be destroyed.
- 3) After Allen transcribes the interview, I will then be asked to review my transcript for accuracy and completeness, either on paper or via email.
- 4) I will further reflect with Allen after he has completed the analysis of all of the spouses' responses to ensure that I agree with the themes observed and conclusions to be reported.

I have been advised that the total anticipated time commitment will be approximately 3 hours or less, including 60-90 minutes for the interview, 30 minutes of reflection and consultation with Allen, and about 60 minutes reviewing the data, over the course of 3-4 months. As a participant in this project, I have the following rights: confidentiality, respect, full assistance and cooperation from the principal researcher, and access to my responses and the final results of the research.

Potential **risks** of participating as a participant in this project include: emotional or physical discomfort from increased attention during the interview to the experience of

spirituality in my role as a caregiver for a spouse with Alzheimer's disease. As these risks are primarily emotional in nature, I will be given a list of community counseling services to which I can turn in the event I need support related to these risks I might potentially incur as a result of issues that may arise from our participation in the study. Allen will also be available for any questions or referrals by phone or email during and after the study.

Potential **benefits** of participating as a participant in this project include: increased understanding of spirituality and its effects on my life as a caregiver for a spouse with Alzheimer's disease.

Every effort will be made to maintain the confidentiality of my study records. My identity will be kept confidential at all times. Only Allen will have access to my name and contact information. This informed consent page will be stored separately from my actual responses to document my voluntary participation securely and confidentially. It will be the only written record of my identity as a participant in this research project. All other records will be maintained using pseudonyms. To increase confidentiality, all data will be stored in a locked file cabinet for 5 years, and then destroyed. I have been advised that the data collected from the study will be used for educational and publication purposes; however, I will not be identified by name. The confidentiality of the data will be maintained within allowable legal limits.

I am aware that no financial remuneration will be offered for participation in the study. I also understand that I will receive no direct payment for my participation in this research.

I have been told that the investigator has the right to withdraw me from this study at any time. The investigator has offered to answer all my questions. If I have additional questions during the course of this study about the research or any related problem, I may contact the principal investigator Allen Novian, by phone at (210) 414-2283 or by email at allen_novian@hotmail.com.

My signature below acknowledges my voluntary participation in this research project. Such participation does not release the investigator or the institution from their professional and ethical responsibility to me. **I have read the information provided above and any questions have been answered to my satisfaction. I voluntarily agree to participate in this study. I have received a copy of this consent form.**

Name (please print)

Date

Signature of Research Participant

Date

Signature of Principal Investigator

Date

ANY QUESTIONS REGARDING YOUR RIGHTS AS A RESEARCH PARTICIPANT MAY BE ADDRESSED TO THE ST. MARY'S UNIVERSITY INSTITUTIONAL REVIEW BOARD HUMAN SUBJECTS (210) 436-3315. ALL RESEARCH PROJECTS THAT ARE CARRIED OUT BY INVESTIGATORS AT THE UNIVERSITY ARE GOVERNED BY REQUIREMENTS OF THE UNIVERSITY AND THE FEDERAL GOVERNMENT.

Referrals

St. Mary's Family Life Center- (210) 436-3133
One Camino Santa Maria
San Antonio, TX 78228

Our Lady of the Lake Counseling Service- (210) 434-1054
Holy Cross Family Practice Association Building
590 N General McMullen
San Antonio, TX 78228

Jewish Family Services- (210) 302-6920
12500 NW Military #275
San Antonio, TX 78231

Alzheimer's Association- (210) 822-6449
7400 Louis Pasteur #200
San Antonio, TX 78229

United Way Help Line- Dial "211"

Appendix C

Demographic Questionnaire

Date _____

Demographic Information

1. Name _____

2. Age _____

3. Phone # Home: _____

Cell: _____

4. Gender Male Female

5. Children

Number []]

Ages []]

6. Religion

 Catholic Lutheran Methodist Baptist Judaism Buddhism Islam No religion Other _____

7. Ethnicity

 Caucasian Hispanic Native American Asian African-American Other _____

8. Education (mark highest level attained)

- less than high school
 high school graduate
 technical/vocational school
 some college
 college graduate
 graduate/professional degree _____(specify)
 other _____(specify)

9. Approximate year of onset of patient's disease _____

10. Approximate date of diagnosis of patient's disease _____

11. Does the patient attend day care or have any other hired helper at home besides the caregiver?

- Yes No

If yes, for how many days per week? _____

How many hours per day? _____

12. List any medications that you are taking.

13. Medical Conditions

Do you have or have you had any medical problems?

- Yes No

If yes, provide a brief explanation. _____

Rate your answers to the following questions:

14. How difficult do you find your caregiving responsibilities?

Very
Difficult

Not At All
Difficult

0 1 2 3 4 5

15. How well do you believe you handle your caregiving responsibilities?

Very Badly

Very Well

0 1 2 3 4 5

Curriculum Vita

DONALD ALLEN NOVIAN JR.

16210 Robinwood Lane
San Antonio, TX 78248
allen_novian@hotmail.com
(210) 414-2283

SUMMARY

- Extensive clinical and research experience.
- Assisted in preparing federally funded studies.
- Experienced in conducting research studies involving both qualitative data and quantitative data.
- Career has included counseling individuals, couples, families, and groups in a variety of settings, project management, supervising and training personnel, organizing and composing study results for publication or presentation at professional conferences, managing budgets, and interacting within the medical/professional community.

EDUCATION

ST. MARY'S UNIVERSITY

San Antonio, Texas
PhD candidate/ Marriage & Family Therapy
Expected graduation May 2008

Master of Arts/ Marriage & Family Therapy
Graduated 2003

UNIVERSITY OF TEXAS AT SAN ANTONIO

San Antonio, Texas
Bachelor of Arts/ Psychology
Graduated *Summa cum Laude* 2001

LICENSURES AND CERTIFICATIONS

Licensed Professional Counselor (LPC)

Licensed Marriage & Family Therapist (LMFT)

PARAMOUNT WELLNESS INSTITUTE, Boulder, Colorado
Holistic Stress Management Instructor
2004

EXPERIENCE

AUDIE L. MURPHY VA HOSPITAL

San Antonio, Texas

Psychology Technician

2001-Present

- Assist in co-leading support groups, qualitative data compilation and other data analysis related to the Stress-Busting Program for Caregivers of individuals with Alzheimer's or Parkinson's Disease
 - Co-lead weekly support group sessions involving caregivers at various locations throughout the San Antonio and surrounding area.
 - Developed and edited modules included in the Stress-Busting program.
 - Revised curriculum for caregivers of individuals with Alzheimer's disease to be specific to Parkinson's disease caregivers.
 - Developed modules to train personnel to lead weekly group sessions.
 - Developed and maintain a process and tracking system of clinical aspects of grant and protocol related paperwork.
 - Responsible for record keeping and appropriate records for IRB, and human subject protocols.
 - Scheduled, conducted, reviewed and analyzed biofeedback sessions with study participants, personnel, and principal investigator.
 - Conducted pre-screen interviews of study participants to assess for personality disorders and other psychological conditions that would inhibit them from participation in a group setting. Provided referral sources for participants ruled out of study on this basis.
 - Counseled study participants with various concerns including stress, family and spouse relationship issues, grief and loss, anxiety, depression and other disorders related to the role of caregiving for someone with Alzheimer's or Parkinson's disease.
 - Input and analyzed qualitative data using N6 and quantitative data using SPSS and Excel.
 - Presented on various topics regarding caregiver stress and solutions throughout city and community.

EXPERIENCE (continued)**ST. MARY'S UNIVERSITY**

San Antonio, Texas

Research Assistant

2004-2006

- Coordinated and trained therapists in Neurofeedback under the supervision of Randal Lyle Ph.D.
 - Coordinated data collection and protocol decisions of therapists for a study of the effects of Neurofeedback on Cognition of senior adults.
 - Conducted Neurofeedback with participants of the study of the effects of Neurofeedback on Cognition of senior adults and clients of the Family Life Center at St. Mary's University.

UNIVERSITY OF TEXAS AT SAN ANTONIO

San Antonio, TX

Research Coordinator

1999-2001

- Assisted principal investigator with data collection, input, and analysis related to a study of the effects of news viewing on levels of stress, anxiety, depression, and anger.
 - Trained study personnel to recruit and conduct quantitative and qualitative phone interviews.
 - Conducted extensive literature review and managed references using Endnotes reference management program.
 - Input and analyzed quantitative data using SPSS.
 - Developed and presented an undergraduate thesis on the relationship between news viewing and anger.

GLAZER'S, HEB, ECKERD'S

Austin and Houston, Texas

1987-1999

- Sales and retail management experience.
- Info provided on request.

THERAPY EXPERIENCE

ST. MARY'S UNIVERSITY

San Antonio, Texas

2001-Present

- 1000 hours of therapy with individuals, couples, families dealing with a variety of issues such as stress management, anger, anxiety, depression, panic attacks, marital discord, separation/divorce, co-dependency, drug addictions, alcoholism, blended family conflicts, OCD, phobias, and issues arising from being a single parent, spiritual/ religious faith confusion, or adolescent difficulties.
- 500 hours of Neurofeedback therapy with adults and children diagnosed with disorders such as autism, attention deficit disorder, reactive attachment disorder, conduct disorder, and generalized anxiety disorder, depression, panic disorder, and OCD.

AUDIE L. MURPHY VA HOSPITAL

San Antonio, Texas

Psychology Technician

2001-Present

- 300 hours facilitating psycho-educational support groups with caregivers of individuals diagnosed with Alzheimer's or Parkinson's disease.
- 500 hours of Biofeedback assessment with caregivers of individuals diagnosed with Alzheimer's or Parkinson's disease. Biofeedback measures included EMG, skin conductance, temperature, blood volume pulse, and respiration.

AREAS OF EXPERTISE

- Individuals, couples, families, and groups
- Stress management
- Caregiver issues surrounding Alzheimer's and Parkinson's disease
- Spirituality
- Autism
- Neurofeedback
- Biofeedback
- Hypnotherapy
- Reike

PRESENTATIONS

Anxiety, depression, and television news viewing. 47th Annual Convention of the Southwestern Psychological Association. Poster Presentation. Houston, Texas. April, 2001.

Stress, the news media, and the September 11th terrorist attacks. 48th Annual Convention of the Southwestern Psychological Association. Poster Presentation. Corpus Christi, Texas. April, 2002.

PRESENTATIONS (continued)

Coping techniques for the family caregiver. St. Paul's Lutheran Church. Presentation for Alzheimer's Association. Hondo, Texas. January, 2003.

Coping techniques for the family caregiver. Karnes City Health and Rehab Center. Presentation for Alzheimer's Association. Karnes City, Texas. February, 2003.

Coping techniques for the family caregiver. St. Andrew's Catholic Church. Presentation for Alzheimer's Association. Pleasanton, Texas. March, 2003.

Stress management: A path to wellness. Army Residence Community. Seminar. San Antonio, Texas. December, 2003.

Stress management: A path to wellness for you and your patients. 2004 Dialysis Conference. Workshop. San Antonio, Texas. February, 2004.

Are there differences in emotional responses between Hispanics and Caucasians to being a family caregiver of a patient with Alzheimer's disease. 2004 State of the Science Conference. Poster presentation. Washington, D.C. June, 2004.

Stress management: A path to wellness for you and your patients. Esplanade Gardens Assisted Living. Seminar. San Antonio, Texas. June, 2004.

Stress management: A path to wellness for you and your patients. Audie Murphy VA Hospital. Seminar. San Antonio, Texas. October, 2004.

Stress management: A path to wellness for you and your patients. Kerrville Junior College. Seminar. Kerrville, Texas. October, 2004.

Are acute laboratory stressors effective in biofeedback testing? 35th Annual Convention of the Applied Association of Psychophysiology and Biofeedback. Poster presentation. Colorado Springs, Colorado. April, 2004.

Psychophysiological and natural killer cell responses to relaxation therapy. 36th Annual Convention of the Applied Association of Psychophysiology and Biofeedback. Poster presentation. Austin, Texas. April, 2005.

Mexican American and white caregivers: Are they different? 37th Annual Convention of the Applied Association of Psychophysiology and Biofeedback. Poster presentation. Portland, Oregon. April, 2006.

Biofeedback and Moderately to Severely Depressed Subjects. 38th Annual Convention of the Applied Association of Psychophysiology and Biofeedback. Poster presentation. Monterey, California. February, 2007.

Computer Program Knowledge

Microsoft Office (Word, Excel, Power Point, Publisher)

SPSS

N6

Endnotes

Biograph, Infinity, and Nexus-10 Biofeedback/Neurofeedback Software and Hardware

Respirate

Freeze Framer

References

Provided on request.