

COUPLES' CONSTRUCTION OF MEANING OF AN ALZHEIMER'S DISEASE  
DIAGNOSIS: A SYSTEMIC APPROACH

by

KATHERINE JEAN DANIELS

B.S., University of Missouri, 2002

M.S., East Carolina University, 2004

AN ABSTRACT OF A DISSERTATION

submitted in partial fulfillment of the requirements for the degree

DOCTOR OF PHILOSOPHY

School of Family Studies and Human Services

College of Human Ecology

KANSAS STATE UNIVERSITY

Manhattan, Kansas

2008

## Abstract

Alzheimer's disease (AD) is a chronic illness that has the capacity to impact several domains of a person's life. The purpose of this qualitative study was to explore four particular domains of meaning of an AD diagnosis to gain a systemic understanding of couples' experiences when one spouse had recently been diagnosed with Alzheimer's disease. A social constructionist framework was used in conjunction with the biopsychosocial-spiritual model, to explore the biological, psychological, social, and spiritual factors which inform and possibly influence couples' experiences in relation to an AD diagnosis. The interview guide was constructed using the underlying biopsychosocial-spiritual framework for the purpose of exploring couples' experiences in a systemic manner. Four couples were interviewed in their homes, no more than two months following a formal diagnosis of AD. This particular time frame captured the raw experience couples went through when receiving an AD diagnosis. All interviews were recorded, transcribed, and analyzed according to a modified version of Moustakas' phenomenological method of analysis. A family medicine physician served as the co-interpreter throughout the entire analysis process. Results consisted of unique descriptions for each couple's case and a composite description of the cross-case analysis, highlighting similarities and differences among cases. The biopsychosocial-spiritual model was found to be a significant tool for eliciting a systemic understanding of each couple's experience, and recognizing unique aspects of couples' experiences. Analysis across cases revealed 14 common themes that emerged across the four (five biological, four psychological, four social and two spiritual) domains. Results revealed that of the 14 common emerging themes, five themes were shared by all cases: *Recognizing a Problem, Experience of Diagnosis Process, Experience of Symptoms, Social Support, and Social Activities*. The overall analysis illustrated many more similarities among biological experiences than any other domain of experience. One case, #3, displayed a particularly unique psychological experience, as well as a significant spiritual foundation. Overall, this study emphasized the importance of using a systemic framework, such as the biopsychosocial-spiritual model, to gain a rich, in-depth understanding of how different couples experience the diagnosis process of AD.

COUPLES' CONSTRUCTION OF MEANING OF AN ALZHEIMER'S DISEASE  
DIAGNOSIS: A SYSTEMIC APPROACH

by

KATHERINE JEAN DANIELS

B.S., University of Missouri, 2002

M.S., East Carolina University, 2004

A DISSERTATION

submitted in partial fulfillment of the requirements for the degree

DOCTOR OF PHILOSOPHY

School of Family Studies and Human Services

College of Human Ecology

KANSAS STATE UNIVERSITY

Manhattan, Kansas

2008

Approved by:  
Major Professor  
Dr. Rick Scheidt

# **Copyright**

KATHERINE JEAN DANIELS

2008

## Abstract

Alzheimer's disease (AD) is a chronic illness that has the capacity to impact several domains of a person's life. The purpose of this qualitative study was to explore four particular domains of meaning of an AD diagnosis to gain a systemic understanding of couples' experiences when one spouse had recently been diagnosed with Alzheimer's disease. A social constructionist framework was used in conjunction with the biopsychosocial-spiritual model, to explore the biological, psychological, social, and spiritual factors which inform and possibly influence couples' experiences in relation to an AD diagnosis. The interview guide was constructed using the underlying biopsychosocial-spiritual framework for the purpose of exploring couples' experiences in a systemic manner. Four couples were interviewed in their homes, no more than two months following a formal diagnosis of AD. This particular time frame captured the raw experience couples went through when receiving an AD diagnosis. All interviews were recorded, transcribed, and analyzed according to a modified version of Moustakas' phenomenological method of analysis. A family medicine physician served as the co-interpreter throughout the entire analysis process. Results consisted of unique descriptions for each couple's case and a composite description of the cross-case analysis, highlighting similarities and differences among cases. The biopsychosocial-spiritual model was found to be a significant tool for eliciting a systemic understanding of each couple's experience, and recognizing unique aspects of couples' experiences. Analysis across cases revealed 14 common themes that emerged across the four (five biological, four psychological, four social and two spiritual) domains. Results revealed that of the 14 common emerging themes, five themes were shared by all cases: *Recognizing a Problem*, *Experience of Diagnosis Process*, *Experience of Symptoms*, *Social Support*, and *Social Activities*. The overall analysis illustrated many more similarities among biological experiences than any other domain of experience. One case, #3, displayed a particularly unique psychological experience, as well as a significant spiritual foundation. Overall, this study emphasized the importance of using a systemic framework, such as the biopsychosocial-spiritual model, to gain a rich, in-depth understanding of how different couples experience the diagnosis process of AD.

## Table of Contents

List of Tables .....	xi
Acknowledgements.....	xii
Dedication.....	xiii
CHAPTER 1 - Introduction .....	1
Statement of Problem.....	2
Definition of Terms .....	5
Theoretical Perspectives .....	6
Purpose of Study.....	6
Significance of Study.....	7
CHAPTER 2 – Literature Review .....	8
Overview of Chronic Illness and Relationships .....	9
Social Constructionist Perspective.....	10
Justification of Social Construction for this Study.....	11
Illness as context bound.....	12
Attributions of causality are derived from theories.....	12
No absolute truth about illness.....	13
Interactive and self-influencing process linking patients and providers.....	13
Biopsychosocial Approach to Illness.....	14
Psychosocial Impact of a Diagnosis of Dementia.....	15
Adjustment to Illness and Coping Strategies .....	16
Marital Perspectives and Perceptions .....	17
Alzheimer’s Disease .....	17
History.....	18
Neuritic Plaques.....	18
Neurofibrillary Tangles.....	18
Loss of Connection between Cells and Cell Death.....	19
Dementia .....	19
Symptoms of Alzheimer's Disease.....	20

Clinical Manifestations of Alzheimer's Disease.....	21
Phases of Alzheimer's Disease.....	22
Diagnosis Process.....	23
Alzheimer’s Disease and the Couple Relationship.....	24
CHAPTER 3 - Methodology .....	26
Qualitative Approach.....	26
Research Design .....	27
Research Questions.....	27
Sample.....	28
Data Collection Strategies.....	29
Question Formation.....	29
Interview Questions.....	30
Interview Guide.....	30
Credibility of Researcher.....	33
Bias Statement of Primary Investigator.....	33
Bias Statement of Co-Interpreter.....	34
Data Analysis .....	35
Analysis Strategy.....	35
Analysis Instructions.....	35
Investigator Reflections .....	40
Primary Investigator Impressions.....	40
Co-Interpreter Impressions.....	41
Verification .....	42
Determination of Substantive Significance.....	42
Standards of Quality Verification.....	43
Strengths and Limitations .....	44
CHAPTER 4 - Results .....	46
Review of Research Questions .....	46
Within-Case Analysis .....	47
Overview of Demographics.....	47
Case One: David and Paula.....	48

Background.....	48
Investigator's Impressions.....	48
Biological Themes.....	49
Psychological Themes.....	51
Social Themes.....	54
Spiritual Themes.....	57
Case Summary.....	58
Case Two: May and Chris.....	59
Background.....	59
Investigator's Impressions.....	59
Biological Themes.....	60
Psychological Themes.....	61
Social Themes.....	62
Spiritual Themes.....	64
Case Summary.....	65
Case Three: Steven and Beth.....	65
Background.....	65
Investigator's Impressions.....	66
Biological Themes.....	66
Psychological Themes.....	68
Social Themes.....	69
Spiritual Themes.....	71
Case Summary.....	72
Case Four: Allison and Dean.....	72
Background.....	72
Investigator's Impressions.....	73
Biological Themes.....	73
Psychological Themes.....	75
Social Themes.....	77
Spiritual Themes.....	79
Case Summary.....	79



Summary of Within-Case Analysis.....	80
Cross-Case Analysis .....	82
Similarities.....	82
Common Themes Shared by All Cases.....	82
Recognition of a Problem.....	83
Experience of Diagnosis Process.....	83
Experience of Symptoms.....	84
Social Activities.....	84
Social Support.....	85
Parallel Themes.....	85
Differences.....	89
Summary.....	91
CHAPTER 5 – Discussion.....	92
Overview of Study .....	92
Purpose.....	93
Summary of Findings.....	93
Discussion of Findings.....	93
Social Construction of Meaning.....	94
Making Sense of AD is a Gradual Process.....	94
Meaning is Derived from Biopsychosocial-Spiritual Experiences.....	95
Meaning is Constructed One Day at a Time.....	97
Worries about the Future Emerge During the Process of Meaning Construction.....	97
A Couple's Social Context is Important to Adjusting to an AD Diagnosis.....	98
Unique Contributions.....	99
Strengths and Limitations .....	99
Strengths of the Study.....	100
Limitations of the Study.....	101
Future Implications .....	101
Clinical Implications.....	102
Research Implications and Future Directions.....	103
Conclusion .....	104

References Or Bibliography .....	104
Appendix A – Recruitment Flyer.....	110
Appendix B – Informed Consent .....	112
Appendix C – Interview Guide .....	116
Appendix D – Case One: Complete Themes and Examples.....	119
Appendix E – Case Two: Complete Themes and Examples .....	126
Appendix F – Case Three: Complete Themes and Examples.....	130
Appendix G – Case Four: Complete Themes and Examples.....	133

## List of Tables

Table 2.1 Three Stages of Alzheimer’s Disease .....	22
Table 3.1 Example From Case Three Coded Transcript.....	37
Table 3.2 Example From Case Three Category Chart .....	38
Table 3.3 Example From Case Three Final Theme Chart .....	39
Table 4.3 Individual Case Themes.....	81
Table 4.4 Common Themes Among Cases.....	87
Table 4.5 Unique Themes .....	90

## **Acknowledgements**

I first want to acknowledge Dr. Jenni Buescher, my co-interpreter who graciously engaged in the entire analysis process with me. Her insight and knowledge contributed to my own learning process, as well as, the overall quality of the study. I am appreciative of her willingness to learn and dedication to this process.

I want to acknowledge my major professor, Dr. Rick Scheidt, and my committee members, Dr. Karen Myers-Bowman, Dr. Candy Russell, and Dr. Carol Anne Holcomb for their ongoing support and encouragement. I have appreciated learning from all of you and your unique expertise.

Last, but not least, I am incredibly blessed to have the unconditional support of my friends and family who have walked by my side throughout this entire process. I am especially thankful for my partner and best friend, Andy Kueny, for his constant love, encouragement, humor, and most of all, patience. Thank you for believing in me and lifting me up when I needed it.

## **Dedication**

This dissertation is dedicated to all of the couples who participated in the study and had the courage to share such an intimate part of their lives with me. I will never forget your generosity and strength.

## CHAPTER 1 - INTRODUCTION

*“Jane was diagnosed with Alzheimer’s disease (AD) almost five years prior to the first research interview; yet Tom and Jane began their journey as husband and wife nearly 63 years ago. When the first interview was conducted with Jane and Tom, the primary investigator was greeted with warm smiles as the couple opened up their home and promptly started pointing out pictures and paintings that were illustrative of their lives together. The couple sat close together on one side of the couch, and frequently reached for one another’s arms or hands throughout the interview...About 10 minutes into the first interview the primary investigator noticed that Jane’s AD was further along than was initially anticipated. At times, it was difficult to understand her response, but other times she was very clear at expressing her thoughts. Although the stories Jane told did not always make sense, her eyes lit up whenever a question was asked about her marriage with Tom. As illustrated in the results below, Jane’s comments were often short and illustrative of a tangential thought pattern. However, when positive comments were made by Jane and followed with grins from Tom, it was clear that although she could not recall specific details of their marriage, she did seem to remember her feelings about their relationship.”*  
(Daniels, Lamson, & Hodgson, 2007, p. 167).

The above quote was included to provide a framework from which this study originated and share a little about my passion for this research, as the primary investigator. The research above was based on a case study of one couple’s marriage, in which the wife was in the late stages of Alzheimer’s disease (AD). That particular case study sparked my curiosity about how marriages are impacted when one spouse gets diagnosed with AD. Although I was impacted greatly by the previous case study, it barely scratched the surface and raised many more questions for me. As a family therapist working in an internal medicine residency program, I was grounded in Engle’s (1977) biopsychosocial approach to assessing and treating illness. I had been taught that in order to fully understand what a person is experiencing, you must use a systemic lens to learn about his or her experience. More specifically, my beliefs as a systemic therapist have been consistent with George Engle’s belief that biomedical problems do not exist without psychosocial implications and psychosocial problems do not exist without biomedical implications. Therefore, since I was interested in understanding how couples experience and

make sense of an AD diagnosis, it seemed only natural to do so from a biopsychosocial-spiritual perspective.

As AD, a progressive and chronic illness, has become more common among the elderly, it is bound to become a more common issue for clinicians and healthcare providers with each year that passes. Therefore, it is important that healthcare providers understand the experience of being diagnosed with AD in order to provide effective care for those individuals, couples, and families. The biopsychosocial model has become well-known over the past several decades as a comprehensive approach to treating and understanding chronic illness. More recently, researchers have begun to study the experience of AD from a psychosocial perspective. While the symptoms of AD directly influence individuals, the changes that occur over time reverberate throughout all of their relationships, perhaps mostly in the couple relationship. Researchers have started to explore AD from a couple's perspective but have yet to explore how couples experience the diagnosis of AD from a biopsychosocial-spiritual perspective. This study was focused on exploring couples' experiences of a diagnosis of AD in hopes of better understanding what couples experience in order for clinicians and other healthcare providers to provide better care for couples faced with AD.

### **Statement of the Problem**

Approximately 5.2 million Americans today are diagnosed with the progressive, degenerative disease referred to as AD (Alzheimer's Disease & Related Disorders Association, Inc., 2008). Unless a cure is found, 14 to 16 million Americans are expected to receive a diagnosis of AD by the year 2050. While a small percentage of individuals develop AD in their 30's, 40's, and 50's, one in ten individuals over the age of 65 develop AD (Alzheimer's Disease & Related Disorders Association, Inc., 2008). Therefore, as the aging population continues to grow, AD also continues to grow and impact more individuals, couples, and families each year. Following the onset of symptoms, an individual with AD will live an average of eight years, but may live as long as 20 years (Alzheimer's Disease & Related Disorders Association, Inc., 2008). A diagnosis of AD is life-changing, not only for diagnosed individuals, but also for those close to them (Alzheimer's Disease & Related Disorders Association, Inc., 2008).

Individuals diagnosed with AD tend to require more behavioral and social support than medical management. Although, no known treatment is available, research has shown that lives'

are better if individuals impacted by AD take full advantage of treatment, care, and support. A systemic understanding of the diagnosis process will assist healthcare providers in delivering more efficient and appropriate care. Therefore when striving to make sense of couples experience of a diagnosis of AD, a multifaceted approach such as the biopsychosocial-spiritual model will yield more valuable information than a single sided approach (e.g., biomedical, or psychological only).

Many researchers have focused on the impact AD has on various individuals, such as caregivers, children and spouses, as well as his or her perceptions of the relationship (Butcher, Holkup, & Buckwalter, 2001; Gubrium, 1988; Mace & Rabins, 1999; Sanders et al., 2008). Researchers have begun to study the experience of being diagnosed with the disease both from a patient perspective (Hagerty Lingler, Nightingale, Erlen, Kane, Reynolds III, Schulz, & DeKosky, 2006; Pearce, Clare, & Pistrang, 2002; Pratt & Wilkinson, 2003), and a couples perspective or marriage emphasis (Daniels et al., 2007; Gallagher-Thompson, Dal Canto, Jacob, & Thompson, 2001; Garand, Dew, Urda, Hagerty Lingler, DeKosky, & Reynolds III, 2007; Robinson, Clare, & Evans, 2005; Wright, 1991). The impact of AD on the caregiver-patient relationship is portrayed primarily from the caregiver's perspective and tends to center around certain themes. Role changes (Mace & Rabins, 1999), caregiver satisfaction, support (Butcher, et al., 2001), and intimacy (Butcher et al., 2001; Gubrium, 1988), are a few of the common topics presented in the current literature.

Throughout the AD caregiver literature, spouses with AD may be included as research participants but rarely receive equal attention in the studies as caregivers, spouses, or other family members (Blieszner & Shifflett, 1990; Butcher et al., 2001; Gubrium, 1988). This means that although individuals with AD may participate in research, investigators may not represent their voices adequately, or even gather their perspective. This presents a concern, since changes in roles, satisfaction, support, and intimacy are likely to affect the person with AD, in addition to the caregiver. Research studies on the dynamics of spousal relationships, where both the person with AD and their spouse caregiver are equally represented in the study, are scarce.

When one spouse develops a dementing illness, the relationship between spouses is expected to change in several ways (Mace & Rabins, 1999). Unfortunately, few studies have been conducted that focus on the impact of AD on the marital relationship with both spouses being studied at the same time, which would allow a more accurate representation of the couple



relationship than studying just one partner of the relationship (Wright, 1991). Wright compared various aspects of the marital relationship when one spouse is in the early-middle stages of AD with couples in which both spouses are free of illness. The results of the study showed that tension, companionship, affection, and sexuality are all impacted when AD is present. More recently, Linda Clare (2002; 2004) has published several articles on AD, reactions to diagnosis, and couples' adjustment to the diagnosis.

Since there is a limited amount of literature focusing on AD and spousal relationships, an assessment of the research on chronic illness and couples' relationships is critical in order to gain an adequate understanding of how a spousal relationship is impacted by a chronic illness, (i.e., AD). Although the representation is not equal among spouses with and without the illness, the literature on chronic illness and spousal relationships is still helpful in understanding common themes associated with the spousal relationship when one spouse has a chronic illness (e.g., cancer, Parkinson's disease, multiple sclerosis, etc.). The themes most commonly associated with the topic of chronic illness and spousal relationships include marital adjustment to their spouses' illness (Foxall, Ekberg, & Griffith, 1985), coping strategies and challenging issues (Habermann, 2000), patient and spouse perspectives on illness (Habermann, 2000; Heijmans, DeRidder, & Bensing, 1999), and perceptions of marital satisfaction (Hafstrom & Schram, 1984). While the research focuses on relationships and chronic illness, only one of these studies actually includes both spouses in the sample. Heijmans et al. (1999) included both spouses in their study. However, they interviewed each partner separately, not examining the dynamics of the relationship. Research on chronic illness and spousal relationships is helpful for the purpose of identifying common issues that are present following the onset of an illness. However, a study that focuses on the AD diagnosis and the couple relationship, while including both spouses, is needed to better understand the diagnosis experience as it relates to couples' relationships.

Wright (1991) mentioned in her research that shared meanings between spouses are often mismatched for various aspects of the relationship, such as expressing tension and sexuality. Her finding of non-shared meanings is a result of collecting both spouses input. In other words, since Wright collected both viewpoints in her study, she was able to see that one spouse could view the couple as having shared meanings about an aspect that the other spouse did not. In the present study, I will use the technique of collecting both viewpoints, as Wright did, so that shared and non-shared meanings may be found throughout the couple's story about their experience with

AD. Using social constructionism as the theoretical framework for this study, this research explores the biosychosocial-spiritual factors that inform us about how couples experience a diagnosis of AD.

### **Definition of Terms**

The definitions of certain terms and concepts were provided to inform the reader of how the concepts were defined and used for this particular study. The mini-mental state examination (MMSE) was used in this study to identify the severity of the participant with AD at the time of the interview. The MMSE is a test that is used most commonly by healthcare providers to assess mental function. The MMSE consists of a series of questions designed to test a range of everyday cognitive skills, with the maximum score of 30. A score of 20 - 24 suggests mild dementia, 13 - 20 suggests moderate dementia, and less than 12 indicates severe dementia. Although MMSE scores of each participant will not be revealed to protect confidentiality, each participant's scores were reported and used to identify the severity of AD at the time of the interview.

Because the focus of this study is on the meanings couples construct, it is first important to provide a definition of *couple meaning*. Borrowing from Patterson and Garwick's (1994) definition of family meaning, *couple meanings* are the interpretations, images, and views that have been constructed by spouses and/or partners "as they interact with each other; as they share time, space, and life experience; and as they talk with each other and dialogue about those experiences" (p. 2). Couple constructions are a product of the couple's interactions which belong to the couple as a unit, rather than belonging to one spouse or the other. Most all meanings that emerged from this study are *couple meanings* because of the focus of the research being the couple unit, rather than the individual participants.

According to a social constructionist perspective, the meaning attached to relationships is not static but a dynamic. In this particular study, the *meaning* of a relationship is best understood as a process, capable of growth, change, and adjustment over time. This perspective of meaning seemed to be appropriate for understanding how couples make sense of an AD diagnosis. Because most cases of AD are diagnosed later in life, it is likely that the meaning of a couple's relationship has already been constructed, maintained, and re-constructed throughout the course of their marriage. When AD is introduced in their marriage, the meaning of a couple's

relationship is likely to change in some way, shape, or form. However, instead of assuming if and how the meaning of a couple's relationship has changed following an AD diagnosis, a social constructionist perspective allows couples to construct that unique meaning together. However, it is important to note that this study only captures the meaning at one phase of couples' journeys, shortly following the diagnosis of AD.

### **Theoretical Perspectives**

Two theoretical perspectives served to inform the purpose, methodology, and analysis of this study. A social constructionist framework was used in conjunction with the biopsychosocial-spiritual model, to explore the biological, psychological, social, and spiritual factors which inform and possibly influence couples' experiences in relation to an AD diagnosis. Social constructionism provided a general framework for understanding the construction of meaning in regards to an AD diagnosis, while the biopsychosocial-spiritual model encouraged a systemic inquiry about the experience. Anderson (2002) defined social constructionism as the idea that beliefs about everyday concepts, such as marriage, are created and maintained by studying the social processes represented in society. She also recognized that through our everyday social interactions we attribute meaning to all aspects of our lives. Considering that AD is an ambiguous illness for many couples to encounter, a social constructionist perspective was viewed as an appropriate approach for exploring how couples make sense of the illness.

### **Purpose of the Study**

The purpose of this study was to explore how couples experience and make sense of a diagnosis of AD from a biopsychosocial-spiritual perspective. The following research questions guided the study: 1) How do couples experience and make meaning of the process, prior to, during, and following one spouse being diagnosed with AD? 2) What do married couples experience physically (signs, symptoms, behaviors) and medically (interaction with physicians, process of diagnosis, medications, examinations) throughout the process of one spouse being diagnosed with AD? What do married couples experience mentally (thoughts, questions, concerns) and emotionally (feelings, moods, emotions) throughout the process of one spouse being diagnosed with AD? 3) What do married couples experience socially throughout the process of one spouse being diagnosed with AD (relationships, activities, support, interactions)

4) What roles do religion and/or spirituality have for couples' experiences of receiving a diagnosis of AD (beliefs, morals, values, perspectives, and approaches) 5) What are some similarities and differences of how various couples experience the process of receiving an AD diagnosis?

The biopsychosocial-spiritual framework (Engle, 1977; 1980) provided a guide for exploring the meaning of couples' experiences in a systemic manner. Use of this framework guided the process of constructing questions that were congruent to this systemic model of healthcare. The present qualitative study employed a phenomenological approach for exploring the phenomenon of couples' experiences of the diagnosis of AD. The study was strongly guided by the theoretical framework of social constructionism. Furthermore, shared meanings created by the couple will be explored among the biopsychosocial-spiritual dimensions, as well as how those meanings are constructed.

### **Significance of the Study**

In contrast to other studies on AD, the current study is unique in that it gathered couples' shared perspectives of experiencing an AD diagnosis from a biopsychosocial-spiritual approach. Four couples were interviewed for the purpose of exploring their experience after one spouse received a diagnosis of AD. To capture their recent experience of the diagnosis process, the interviews were collected within two months of couples receiving a formal AD diagnosis. The study focused on how couples made sense of an AD diagnosis by exploring the biological, psychological, social, and spiritual dimensions of their experience. The biopsychosocial-spiritual framework questioning added a unique component to this study and enhanced the depth and significance of the study. The interviews were analyzed using a modified phenomenological analysis strategy (Moustakas & Douglass, 1985) to extract the meaning of couples' experiences along the various dimensions.

## **CHAPTER 2 - LITERATURE REVIEW**

Currently, over 5 million Americans have been diagnosed with Alzheimer's disease (AD), the most common form of dementia (Alzheimer's Disease & Related Disorders Association, Inc., 2008). Unless scientists find a way to effectively prevent or treat AD, the number of individuals older than 65 years of age living with the disease could range from 11 to 16 million Americans by the year 2050. As the average life expectancy rises, the number of Americans with AD is expected to rise as part of the aging population (Alzheimer's Disease & Related Disorders Association, Inc., 2008). This presents a need for healthcare providers to be knowledgeable and comfortable when working with patients and families impacted by the disease. The following literature review is representative of the current research available to family therapists and other health care providers seeking information about the couple's experience of the AD diagnosis process.

AD impacts not only the individual diagnosed with the illness, but also the relationships in which that person is involved. In the context of this study, a relationship involves the interaction of two people whose lives are interconnected in a mutually influential manner. Berger and Luckman (1966) claimed that all knowledge is derived and maintained through social interactions. According to this perspective, when a couple is faced with a chronic illness, such as AD, the meaning of the diagnosis for the couple relationship is a product of social construction. Each couple faced with an AD diagnosis is likely to make sense of the diagnosis process in a way that is unique to his/her relationship with his/her spouse, healthcare provider(s), and other people with whom he/she interacts throughout their lives. As a basis for this study, the primary investigator holds the underlying notion that when a married individual is diagnosed with AD, the following three separate entities are impacted by that diagnosis: the person, the spouse, and their relationship. A social constructionist perspective, as described later in this chapter, will be used to explore how couples' relationships are impacted by the presence of AD. More specifically, this study explored the meaning couples attributed to the biological, psychological, social, and spiritual dimensions resulting in a systemic understanding of how the participating couples made sense of an AD diagnosis. This literature review is a comprehensive review of research focused on the following areas: (1) overview of chronic illness (2) the social

construction of chronic illness, (3) a biopsychosocial-spiritual approach to chronic illness, (4) background and history of Alzheimer's disease, (5) Alzheimer's disease and couple relationships, and couples adjustment to the diagnosis of Alzheimer's disease, and (6) the use of social constructionism as a perspective for exploring couple's meaning of AD diagnosis. First, an overview of chronic illness in the context of relationships is provided to set a foundation for the remainder of the literature review.

## **Overview of Chronic Illness and Relationships**

In the year 2005, 133 million people, almost half of all Americans, were living with at least one chronic illness (Centers for Disease Control and Prevention, CDC, 2008). The CDC reported that seven out of every 10 American deaths each year are due to a chronic illness (2008). Most chronic illnesses result in a prolonged course of illness and disability which often leads to extended pain and suffering and decreased quality of life for millions of Americans. In 2005, some of the leading causes of death in the United States were heart disease resulting in 652,000 deaths, cancer resulting in 559,000 deaths, and chronic respiratory disease resulting in 131,000 deaths, Diabetes mellitus resulting in 75,000 deaths and Alzheimer's disease resulting in 72,000 deaths (CDC, 2008). Because of the high prevalence of chronic illness in the United States, it is important to understand how a diagnosis of any chronic illness influences relationships before specifically examining the impact of an AD diagnosis.

A review of the literature on chronic illness and spouses provides the opportunity to present issues such as spousal adjustment to illness, coping strategies of spouses, patient and spouse perspectives, and marital perceptions that might also apply to couples dealing with an AD diagnosis. Researchers also have emphasized the role clinicians can play in encouraging couples and families to establish illness-relationship boundaries (Patterson & Garwick, 1994; Rolland, 1994). Rolland (1994) stated that with particularly difficult chronic illnesses, the illness is ever-present and demands continual energy from the couple. He suggested that couples should set limits and boundaries as an attempt to "keep the illness in its place" (Rolland, 1994, p. 331).

Rolland (1994) concluded that when couples face chronic illness, they are faced with the task of defining the illness as "my" vs. "our" problem. When couples approach a chronic illness

as a concern shared by both partners, they are likely to acknowledge physical and psychosocial burdens, as well as acknowledge the illness-related roles of both partners. Rolland explained further that when a couple is faced with a chronic illness, the relationship is presented with the opportunity for growth, as well as risks for deterioration. Other literature on chronic illness and couples is provided later in this chapter.

### **Social Constructionist Perspective**

Roots of the social constructionist perspective stem from work by Berger and Luckman (1966) who described the focus of social constructionism as the discovery of ways in which reality is created and perceived by individuals and groups. Using this framework to guide the present study, this study explores how couples construct meaning surrounding an AD diagnosis from a systemic perspective, consisting of the biological, psychological, social, and spiritual dimensions of their lives. This perspective also implies that just as couples are constructing meaning, the research also is constructing meaning. Therefore, the researcher in this study can be viewed as an active participant in the construction of meaning. A social constructionist approach will be applied in the present study for the purpose of offering insight into the process of meaning construction for couple relationships impacted by an AD diagnosis. “Sometimes in all our concern with prevention, cure, and treatment, we forget that there’s a real, living individual behind the disease” (Gubrium, 1986, p. 91). Twenty years ago, Jaber Gubrium called attention to the fact that individuals with AD often get overshadowed by the actual disease itself. Now, it seems as though in all the concern with patients, family members and caregivers, professionals may be likely to forget that there is a couple relationship behind the disease. It is important for healthcare providers to recognize that when AD enters the life of an individual, it also enters the intimate bond between a husband and a wife, as well as, other relationships in his/her life.

Because little attention has been devoted to understanding the couple relationship and AD, a theoretical framework will offer structure in conceptualizing the process of meaning construction for couples experiencing AD. The underlying philosophy of social constructionism lends itself well to the exploration of how couples construct the meaning of an AD diagnosis for their marital relationship. This understanding is a critical piece of providing effective care to couples faced with the disease. Understanding how AD is a socially constructed phenomenon will help clinicians and other healthcare providers recognize when socially constructed meanings

are prematurely guiding the experience of couples facing AD. Before explaining how the social constructionist perspective can be applied to Alzheimer's disease, it is first important to develop a basic understanding of the core principles which comprise the social constructionist framework. According to Freedman and Combs (1996), the social constructionist worldview is based on the following four ideas: (1) realities are socially constructed, (2) realities are constituted through language, (3) realities are organized and maintained through narrative, and (4) there are no essential truths. These are the four main assumptions which have guided the process of understanding and conceptualizing how couples construct meaning following an AD diagnosis.

### ***Justification of Social Construction for this Study***

The theoretical framework of social constructionism provided a guide for recognizing the biological, psychological, social, and spiritual factors involved in the meaning making process for couples faced with AD. In this phenomenological study, the aim of the primary investigator was to understand how couples make sense of their social world following the diagnosis of AD (Gubrium & Holstein, 2003). A social constructionist perspective helped to "collapse the boundaries between mind, body, and culture", enabling the search for multiple causes, as well as, multiple sources of recovery (Peterson & Benishek, 2001, p. 85). While the focus of this study was not to find causes of AD or sources of recovery, the social constructionist perspective was used to gather a holistic understanding of couple's experiences with AD.

Petersen and Benishek (2001) clarified the distinction between the experience of illness and the conception of illness for the purpose of studying the social construction of cancer for women in therapy. These authors stated that the *experience of cancer* is the physical sensation, whereas the *conception of cancer* is a combination of the label applied to it, as well as the meaning attached to the cancer based on cultural presuppositions. Petersen and Benishek suggested that the label and socially-constructed meaning of cancer often precedes the actual physical, spatial, and social experiences of those diagnosed with cancer. According to this perspective, the socially-constructed meaning of AD is as important to recognize as the biological symptoms of the disease. In this study, a qualitative approach was applied, while using a phenomenological analysis to extract thematic content from the couples' experiences. The social constructionist perspective of illness means that (1) illness is context bound; (2) attributions of causality stem from theories, which are value-laden; (3) there are no absolute



truths about an illness; and (4) the treatment provider and the person with the illness are inextricably bound through a process which is interactive and self-influencing (Petersen & Benishek, 2001). An explanation was provided in the following section on how each one of these aspects fits the current study.

***Illness as context bound.***

The first component is a significant factor to consider when making sense of AD in the context of couple relationships. The idea of an illness being context bound means that it is influenced by an individual's biology, psychology, and his/her social environment (Petersen & Benishek, 2001). Each of these aspects alone, as well as the interaction among them, should be thoroughly examined to gain an understanding of the context in which the couple relationship and the illness reside. First, the biological aspect could be comprised of the sex of the patient, his/her race, the severity of the disease, the age of disease onset, and symptom manifestation. Psychological influences on context could include, but are not limited to, level of insight, status of mental health, personality characteristics, temperament, level of self-esteem, and ways of viewing the world. A couple's social environment could be comprised of their cultural influences/identity/involvement, region in which they live, level of education, occupations, social support, religious or spiritual beliefs, community resources available to them, and context of their meaning of 'home'.

If illness is context bound, then in order to understand how AD impacts couple relationships, characteristics of the context in which the relationship exists must first be understood. It is important that researchers and clinicians understand the overall context of the relationship without separating out the relationship prior to and after AD. This way of dichotomous thinking places unrealistic expectations and assumptions on the couple relationship and forces a prescribed meaning of AD on the couple. Recognition of contextual continuity as well as changes will lend to a more complete understanding of the couple context in which the illness is bound.

***Attributions of causality are derived from theories.***

The second meaning of a constructivist view of illness, as described by Petersen and Benishek (2001), is that attributions of causality are value-laden, mainly because they are based in value-laden theories. The attributions that a patient or couple makes about the causes of AD

are influenced by their personal theories of illness, which are formed in part, by values and their socio-historical context. This indicates the need to inquire about the values and beliefs which inform the causal attributions of patients, partners, couples, and healthcare providers. For example, attributions of causality made by physicians are biologically value-laden since they rest on their beliefs of the science of medicine. Attributions of causality also may be strongly linked to cultural or religious beliefs of the individual with the illness, their spouse, or their family members. This demonstrates the need to examine the biological, psychological, and social-environmental context when learning how couples make sense of an AD diagnosis.

***No absolute truths about illness.***

The third characteristic of the social constructionist view of illness is that there is no absolute truth about an illness. There may be a biological truth about a diagnosis, but that is not equivalent to the attributions regarding why disease occurs in their lives. For example, a biological truth about AD is that it impacts the cognitive impairment of an individual. However, each couple with AD may experience the cognitive impairment in different ways. A social constructionist perspective allows each couple the right to attach their own meaning to the illness, without it being labeled as right or wrong. For example, one couple may believe that AD was part of God's test for the couple's strength of their marriage. However, another couple might believe that one spouse was diagnosed with AD because they did not appreciate life enough. From a social constructionist viewpoint, both of the beliefs would be perceived as real to the couple, rather than being considered an objective reality. This extends to ways of dealing with the illness, with multiple possibilities in which the couple can approach the illness. As a marriage and family therapist, a belief of the primary investigator is that it is important to recognize that an illness such as AD impacts the entire family, and not just the individual diagnosed with AD. According to a social constructionist perspective, each family member's understanding of the illness constitutes a meaning system that will impact their receptivity to new information, their openness to treatment options, and their interaction with other healthcare providers their reality is true for them, whether or not it is true for everyone else.

***Interactive and self-influencing process linking patients and providers.***

The last aspect of the social construction of illness defined by Petersen and Benishek

(2001) is that the person with the illness and the person treating that illness are inextricably bound through a process which is interactive and self-influencing in nature. This highlights the importance of the interaction between patients and healthcare providers, family members, or researchers, as it pertains to the experience and progression of the illness. This is especially true for couples experiencing AD. The way a physician presents the diagnosis, including who he/she speaks to and the language he/she uses could influence the illness perception of both the individual with the disease and his or her spouse. For example, if a physician speaks primarily to the spouse instead of the person with the disease, the spouse with AD could interpret it as if his or her perspective is no longer important, despite the fact that they are still cognitively aware of what is being said. For couples experiencing AD, the interaction between the couple and the healthcare provider significantly influences how the couple approaches its illness experience. Therefore, if a physician approaches the initial diagnosis process by using language that unites the couple in dealing with the AD together, the couple is likely to be influenced by that language. Next, a review of literature on the biopsychosocial approach to illness is provided, since the biopsychosocial model with the other perspective guiding this study.

### **Biopsychosocial Approach to Illness**

George Engle (1977; 1980) developed the biopsychosocial model of healthcare after he recognized important components that were missing from the biomedical model. Engle created the model to include the biological factors of an illness, in addition to the psychological and social factors involved in a patient's health. He thought that the traditional biomedical model, which focuses on the body and disease, was flawed significantly because it did not include the patient and his/her attributes as a human being. As articulated by Seaburn, Gawinski, Harp, McDaniel, Waxman, and Shields (1993), the biopsychosocial model respects the complex interaction of cells, organs, and organ systems, in addition to persons, families, and social systems in the development of problems. An underlying assumption of the model is that a change in any factor (from cells to families) may influence changes in other factors.

Over the past decade, researchers have begun to explore the experience of chronic illness from a biopsychosocial perspective (Kunkell, Bakker, Myers, Oyesanmi, & Gomella, 2000; Ownsworth, Clare, & Morris, 2006; White & Grenyer, 1999). Kunkell et al. (2000) summarized the biopsychosocial aspects of prostate cancer based on a 30 year review of relevant literature.

Their review revealed that various biological, psychological, and social findings that had previously been linked to prostate cancer, even though they were not studied within this framework. Depression, anxiety, and relationship changes were found to be common among the psychological and social aspects related to the disease. They concluded that healthcare providers needed to consider patient and family beliefs when treating prostate cancer.

Based on a 30 year review of literature on the concepts and models of awareness, Clare (2004) developed a biopsychosocial framework for considering awareness in early-stage Alzheimer's disease. Across the three domains Clare identified the biological, psychological, and social factors that should be considered when attempting to understand an individual's level of awareness in the early stages of AD. She identified that at the biological level, disturbances of awareness may appear as a result of cognitive changes that might impair a person's ability to understand their disease and the implications of it. At the psychological level, she stated that individuals' personality, coping styles, values, beliefs, and prior experiences influence how they register changes, react to them, try to explain them, experience emotional impact, and attempt to adjust. Last, she identified that at the social level, the nature of interactions with others influences the expression of awareness.

### ***Psychosocial Impact of a Diagnosis of Dementia***

Researchers have begun to assess the psychosocial impact, the effect on psychological well-being and social relationships, on individuals and family members receiving a diagnosis of dementia and/or AD (Clare, 2002; Pratt and Wilkinson 2001; 2003; Robinson, Clare, & Evans, 2005; Smith & Beattie, 2001). Pratt and Wilkinson (2001; 2003) proposed a psychosocial model to illustrate the experience of individuals receiving a diagnosis of dementia. The purpose of their model was to draw together the social and psychological aspects of individuals' diagnosis experiences with dementia. Pratt and Wilkinson interviewed participants from three different health boards in Scotland. Their participants, ranging from 44-78 years of age, met the following criteria: they had been diagnosed with some form of dementia, the diagnosis had been disclosed and retained, they were identified as able to talk with some insight about their experience, and they were able to provide informed consent. The interviews in the study were guided by themes covering practical aspects of the diagnosis, terms used and support offered, and the emotional impact of receiving the diagnosis. Pratt and Wilkinson developed a model that operates on the

following two axes, which are intended to overlap: 1) the desire and/or ability to know the diagnosis and 2) the social context. Furthermore, the two axes cross to produce the following four quadrants in the model: detachment (an unsupportive social context with a low ability/desire to know the diagnosis), distress (an unsupportive social context with an ability/desire to know the diagnosis), maximizing coping strategies (a supportive social context with a high ability/desire to know the diagnosis), and decline/denial (a supportive social context with a low ability/desire to know the diagnosis). The studies described previously regarding the psychosocial impact of AD lead into literature on the adjustment to illness and coping strategies.

### *Adjustment to Illness and Coping Strategies*

Foxall, Ekberg, Griffith, and Davis (1985) found that the adjustment patterns to chronic illness between chronically ill individuals and their spouses did not significantly differ. They believe this finding is reflective of the impact of chronic illness on both the ill person and his/her spouse, as both adjusted similarly to the illness. The well spouse and his/her ill spouse were studied separately while assessing for the adjustment patterns in the relationship. Over a decade ago, researchers explored family perceptions of living with AD among 38 multigenerational families (Garwick, Detzner, & Boss, 1994). These researchers observed family meanings that were constructed while family members held conversations about their perceptions of AD. They found that families in general expressed uncertainty as they processed the early stages of AD. They also identified that family members focused less on the biological aspects of the disease and were more focused on how AD had disrupted their everyday family life.

Habermann (2000) studied the spousal perspective of Parkinson's disease, a chronic illness, and found that three strategies were common among spouses coping with their challenges: maintaining their own life (continuing everyday activities and contacts), viewing their challenges as secondary (spoke of partner's challenges first), and being encouraging of their spouses to stay active (encourage activities they can enjoy together). Habermann also found that the main challenge spouses dealt with was seeing their spouse struggle through a progressive illness. The spousal perspectives of Parkinson's disease suggest coping strategies and challenges that may be applied to other illnesses as well, such as AD.

### ***Marital Perspectives and Perceptions***

A study by Heijmans, DeRidder and Bensing (1999) focused on patients' and spouses' perspectives of a chronic illness, and how the dissimilarities between patient and spouse perspectives can influence the patients' adaptation to the illness. These researchers demonstrated that spouses without the illness tend to be pessimistic about the time-frame of the illness and also tended to minimize the seriousness of the illness. It must be noted that the minimization of the illness was reported only by the patients and not their spouses. Since the researchers only gathered one perspective (the patient's) on this issue, the results are clearly one-sided.

Another issue addressed within the research literature on chronic illness and spouses is the perception of marital satisfaction of the spouse of someone with a chronic illness. Hafstrom and Schram (1984) found that the marital satisfaction for wives was most often related to the husband's satisfaction, and not to the wife's chronic illness. The researchers noted that more studies are needed to test for differences in husband's satisfaction when his wife has a chronic illness, in addition to the expansion upon the wife's perceptions of her satisfaction in the relationship. Now that the literature on chronic illness and relationship has been reviewed, the following section will provide a background of the specific illness of AD.

### **Alzheimer's Disease**

Since the age group with the highest risk of AD, those 85 and older, is the fastest growing population in the country, healthcare providers can anticipate increasing involvement in the care of patients with AD and their family members (Alzheimer's Disease Education and Referral Center, 2005). Although many factors may influence the risk for AD, the primary predictor of risk for developing the disease is age. Of the 5.1 million Americans with AD, 4.9 million are age 65 or older (42% of these individuals are 85 years or older) (Alzheimer's Disease & Related Disorders Association, Inc., 2008). In early-inherited forms of AD, individuals may receive a diagnosis while in their 30's or 40's. Individuals may live with the symptoms of AD from five to twenty years following formal diagnosis (Mittelman, 2002). Throughout this post-diagnosis period, the disease manifests in the following three areas: impairment of cognitive functions, behavior and psychiatric symptoms, and difficulty in activities of daily living, as discussed in the next section (Burns, Byrne, Maurer, & Lancet, 2002).

## *History*

Over 100 years ago, Alois Alzheimer, a physician, saw a 51-year-old patient who presented with confusion, disorientation, rapid memory loss, and trouble expressing her thoughts (Alzheimer's Disease & Related Disorders Association, Inc., 2008). Intrigued by the unique symptoms and steady progression of her disease, Dr. Alzheimer performed an autopsy after the patient's death, four years following the onset of her symptoms. The autopsy of the brain revealed significant shrinkage, numerous dead and dying cells, and two kinds of here-to-fore unseen microscopic deposits. These brain abnormalities were thought to have caused the symptoms of memory impairment, as well as cognitive and emotional decline (Gruetzner, 1992).

The microscopic deposits discovered by Dr. Alzheimer, neuritic plaques and neurofibrillary tangles, were considered to be the two hallmark characteristics of AD until the last 30 years when the loss of connections between cells and cell death was discovered as another hallmark feature of the disease (Alzheimer's Disease Education and Referral Center, 2005). It was not until the 1960's and 1970's that neurofibrillary tangles and neuritic plaques were found to be the most common neuropathic finding in elderly people with dementia (Burns et al, 2002). While clinical researchers have spent much time searching for the possible etiology of the disease, an exact cause has not been found. The majority of biological researchers have focused on the amyloid hypothesis, which states that unknown factors trigger overproduction of a protein fragment known as beta-amyloid and the brain's ability to dispose of it.

### *Neuritic Plaques*

One of the brain-related structural changes recognized in patients with AD is the excess of beta-amyloid fragments which accumulate into microscopic plaques (Alzheimer's Disease and Related Disorders Association, Inc., 2008). Structures containing amyloid and periodically around blood vessels were identified more specifically, as neuritic plaques (Mace & Rabins, 1999). Every patient diagnosed with AD develops neuritic plaques in areas of the brain necessary for memory and cognitive functioning (Selkoe, 1997). Although it is not clear how amyloid protein is involved in the progression of AD, Mace and Rabins (1999) suggested that the body is not equipped to dispose of these abnormal forms of amyloid protein that develop in the brain.

### *Neurofibrillary Tangles*

The other main structural change found in the brains of people with AD involves neurofibrillary tangles. Neurofibrillary tangles are located inside nerve cells and are described by one researcher as “twisted protein fibers” (Frishman, 1997). Selkoe (1997) described neurofibrillary tangles as “bundles of paired helical filaments,” within the neurons of the brain. He stated that almost all patients with Alzheimer’s disease have neurofibrillary tangles along with neuritic plaques. Tangles result from an overabundance of phosphate molecules attached to the tau protein.

### ***Loss of Connections between Cells and Cell Death***

Over the past 30 years, the gradual loss of connections between neurons was identified as the third major pathological feature of AD (National Institute on Aging, 2005). This process results in the damage of neurons which therefore stop functioning properly and eventually die. As neurons die throughout the brain, the regions affected start to shrink. This process is called brain atrophy (2005). In a healthy brain, information flows in tiny chemical pulses at connections, called synapses, and is released by a neuron and taken up by a receiving cell. These signals move continuously through the brain’s circuits, creating the basis of memories, thoughts, and skills (Alzheimer’s Disease & Related Disorders Association, Inc., 2008). In a brain with AD, information transfer at the synapses gradually fails, leading to a decline in the number of synapses, followed by cell death.

### ***Dementia***

According to the National Alzheimer’s Association (2008), dementia is a term to represent a group of disorders that cause irreversible cognitive decline due to various biological mechanisms that damage brain cells. AD is known as the most common form of dementia, accounting for 50-70% of dementia cases (2008). As defined in the DSM-IV-TR (American Psychiatric Association, 2000), dementia of the Alzheimer’s type is a disease with gradual onset and continued cognitive decline. The cognitive deficits of AD as identified by the American Psychiatric Association are memory impairment and cognitive disturbances including: language disturbance, impaired ability to carry out motor activities, failure to recognize or identify objects, and disturbance in executive functioning (i.e. planning, organizing, sequencing, etc.). Furthermore, for dementia of the Alzheimer’s type to be diagnosed, the cognitive deficits must represent a significant decline from the patient’s previous level of functioning (American



Psychiatric Association, 2000). The definition of dementia of the Alzheimer's type in the DSM-IV-TR encompasses many of the symptoms that are often manifested throughout the course of the disease; however, the various symptoms will be described in more depth in the following section.

### *Symptoms of Alzheimer's disease*

Although the American Psychiatric Association (2000) has identified the main characteristics needed for diagnosing dementia of the Alzheimer's type, a thorough description of the various symptoms that may be present during the course of AD is needed to understand how an individual is impacted by the disease. Symptoms associated with cognitive functioning, behavior, mood, and activities of daily living are expanded upon in this section.

Individuals with a dementing illness, such as AD, may experience several problems associated with cognitive functioning. As an addition to Gwyther's (1985) identification of symptoms, several other symptoms that are representative of the cognitive impairment that occur throughout the duration of AD have been identified (Alzheimer's Disease & Related Disorders Association, Inc., 2008; Gruetzner; 1992). The symptoms related to cognitive impairment include: confusion, memory impairment, disorganized thinking, impaired judgment, inability to learn new skills, inability to define words or concepts, inability to clearly express thoughts or ideas, declining writing and number skills, slower responses, inability to process simple information, inability to complete daily tasks of living, and difficulty making decisions. These cognitive symptoms may influence many of the behavioral symptoms that develop as AD progresses

Although cognitive impairment is a major symptom of AD, behavioral symptoms that later develop are often the most distressing part of the disease for the entire family (Mace & Rabins, 1999). Some of the most disturbing behavioral symptoms are wandering and sleep disturbances. Mace and Rabins stated that wandering is a common behavioral symptom that can be frightening and dangerous to both the patient and other family members. Wandering may result from getting lost, being disoriented, boredom, restlessness or inability to sleep (1999). People with AD often are restless at night, thus resulting in frequent sleep disturbances and night wandering. Additional behavioral symptoms include: hiding things, rummaging through closets or drawers, exhibiting inappropriate sexual behavior, clinging to people, complaining, insulting

others, repetitious actions, demanding things, and not cooperating. These behavioral problems may not exist in all people exhibiting symptoms of AD but are common symptoms associated with the disease. Behavioral symptoms may be influenced by cognitive symptoms such as memory impairment, confusion, and lack of control. Unlike cognitive and behavioral symptoms, indicators associated with mood are not always included throughout the progression of AD.

Individuals with memory impairment may experience problems with their moods, such as: *depression, suicidal thoughts, apathy, anxiety, irritability, nervousness, paranoia, suspiciousness, and self-blaming* (Mace & Rabins, 1999). Symptoms of depression such as sadness, withdrawal, self-neglect, and emptiness are some of the many indicators associated with mood that often accompany AD (Gruetzner, 1992). For some, the depression or anxiety associated with the disease may be so overwhelming that suicide is considered (Mace & Rabins, 1999).

As an individual's cognitive functioning declines, behavior may become problematic (Mace & Rabins, 1999). Moods also may change and daily activities become more difficult. Common symptoms associated with daily living include: *problems eating, difficulty managing personal hygiene, difficulty bathing and dressing, urinary or bowel incontinence, and problems walking* (Mace & Rabins, 1999). Mace and Rabins (1999) noted that when the prevalence of the symptoms associated with carrying out one's daily activities increases, the individual with AD will have more difficulty living independently.

The various symptoms associated with cognitive functioning, behavior, mood, or daily living, all are important in understanding the impact AD has on relationships, in particular the marital relationship. After recognizing the AD symptoms associated with the disease, it is then important to understand how the symptoms manifest.

### ***Clinical Manifestations of Alzheimer's disease***

Burns, Byrne, Maurer, and Lancet (2002) characterized the manifestations of Alzheimer's disease as threefold. AD first leads to deficits in cognitive function such as: *memory loss, language impairment, and the inability to complete motor tasks*. Second, disturbances in behavior and psychiatric symptoms begin to surface such as, *delusions, hallucinations, depression, changes in personality, and misidentification*. Third, activities of daily living become more difficult as the disease progresses. For example, it may be difficult to do any of the following: *make a phone call, drive somewhere, handle money, dress, eat, and use the bathroom*.

The various manifestations of AD illustrate the systemic impact the disease can have on an individual and family life. These manifestations can be understood in more detail when considering the progression of the disease.

***Phases of Alzheimer’s disease***

Researchers have grouped the symptoms of AD into three phases of progression (Mittelman, 2002; Gwyther, 1985) which also include the three categories of manifestation (Burns, Byrne, Maurer, & Lancet, 2002). Gwyther (1985) organized the symptoms of AD into three different stages, and described in further detail, specific symptoms that may appear in each stage of the disease. The stages of AD which Gwyther (1985) structured include many symptoms that may appear at each stage of the disease, but do not necessarily appear in every stage, of every case. The stages of AD progress at different rates for various individuals, and characteristics may be unique for each person diagnosed with the disease (Mittelman, 2002). The following table (Table 1) is included to provide a general outline of the progression of AD, according to Gwyther’s (1985) stages.

**Table 2.1 Three Stages of Alzheimer’s Disease**

	<i>Time Frame</i>	<i>Symptoms</i>
Early	2-4 years (prior to and during diagnosis)	Recent memory loss Forgetfulness Slight confusion Personality changes Trouble making decisions Behavioral changes
Middle	2-10 years (following diagnosis)	Increased confusion Illogical thinking patterns Increased memory loss Lack of control Difficulty completing simple tasks Significant communication problems Delusions
Late	1-3 years (end stage)	Inability to care for self Few communication abilities Inability to control bodily functions Several physical changes Cannot recognize loved ones

Table 2.1 illustrates a general sequence of symptoms and an approximated time frame for each phase. While the table included the primary symptoms of each stage, there are many more symptoms that could occur throughout the duration of the disease that fall under the following

four categories: cognitive symptoms, behavioral symptoms, symptoms associated with mood, and symptoms associated with daily living. The three phases of progression associated with AD are important in understanding the impact AD has on relationships as it progresses with time. An understanding of the progression of symptoms, by stages, helps provide a context for the relationship between AD and caregiving.

### ***Diagnosis Process***

A significant component of AD treatment is providing supportive care for the purpose of helping patients and their loved ones come to terms with the diagnosis, obtain information and advice regarding treatment options, and maximize quality of life throughout the course of the AD (National Institute on Aging, 2005). When receiving a diagnosis of AD, a patient typically will receive one of the following two diagnoses: probable Alzheimer's or possible Alzheimer's. Probable Alzheimer's is diagnosed when all other disorders currently known to cause dementia have been ruled out and the physician has concluded that the symptoms are most likely the result of AD. A physician gives a diagnosis of possible Alzheimer's when AD is probably the primary cause of dementia, but another disorder might be influencing the progression of symptoms (2005).

A recent study was conducted using a pre/post survey on 90 individuals and their partners, prior to and following the diagnosis of Mild Cognitive Impairment (MCI) or AD to examine short-term changes in depression and anxiety after receiving a dementia diagnosis (Carpenter, Xiong, Porensky, Lee, Brown, Coats, Johnson, & Morris, 2008). Their findings demonstrated that individuals and their partners seeking a dementia evaluation do not experience adverse psychological reactions when receiving a diagnosis of MCI or AD. In fact, little change was seen in depressive symptoms, yet symptoms of anxiety seemed to decrease after diagnostic feedback. More specifically, individuals who started their study with high levels of anxiety often experienced significant relief following a formal evaluation and diagnosis. Some individuals were relieved because they were given a clear bill of health, and others were relieved because they finally had an official diagnosis and an explanation for symptoms. These researchers highlighted that there are significant benefits of early diagnosis of MCI and AD, but that diagnosis disclosure should remain sensitive to each individual's circumstances. Robinson, Clare, and Evans (2005) conducted a study exploring the psychological reactions to a diagnosis

of dementia for nine married couples in which one spouse had received a diagnosis of dementia during the previous two years. These researchers used an interpretive phenomenological analysis, in which ten main themes emerged. Of the ten themes that emerged in their study, six of them were similar to themes that emerged in the present study. Couples in Robinson, Clare and Evans study reported changes such as, differences in memory functioning, mood, and temperament.

### *Alzheimer's Disease and the Couple Relationship*

To date, only a few studies have described the marital relationship qualitatively and quantitatively by assessing both spouses together, following the diagnosis of AD (Daniels et al., 2007; Gallagher-Thompson et al., 2001; Garand, Dew, Urda, Hagerty Lingler, DeKosky, & Reynolds III, 2007; Wright, 1991). Wright (1991) investigated the impact of AD on the marital relationship, in which both spouses were studied together. She compared couples in which one spouse had AD to couples in which both spouses were in good health. Wright also focused on different aspects of the marital relationship, rather than focusing only on the caregivers' perspective of the relationship. In addition, she found that shared meanings between spouses often differed when referring to aspects of the marital relationship such as expressing tension, sexuality, and total quality of marriage. Overall, the researcher discovered that when AD was present in a marital relationship, many dimensions of that relationship were affected including: consensus/instrumental (agreement of tasks), tension (perceptions of expressed tension), companionship (perceptions of closeness with companionship), affection (reported affection by spouse and observed touch), and sexuality (agreements over problems with sexual issues). Although Wright's study did include the perspective of the spouse with AD, the majority of current research literature does not include available information concerning the perspective, or voice, of those individuals who have been diagnosed with AD. "Psychosocial inquiry into the disease has been limited to study its impact on caregivers with little attention to impact on patients" (Cottrell & Schulz, 1993, p. 205). These two researchers pointed out that although many individuals with AD are studied everyday, the perspective of the individual with the disease is rarely seen as essential to the research on understanding the implications of the disease.

More recently, researchers interviewed 27 adults living with a spouse with Mild Cognitive Impairment (MCI), for the purpose of understanding how the marital relationship is affected by MCI (Garand et al., 2007). Although the focus of their study was on married couples, only the spouse of the individual with MCI was interviewed. Their result illustrated that a variety of symptoms associated with MCI were perceived as distressing by spouse caregivers. The less the spouse with MCI talked and the more frequent the caregiving spouse had to repeat questions were related to lower levels of marital satisfaction as reported by the caregiver. The researchers concluded that behaviors related to MCI are distressing to spouse caregivers and pose a threat to marital quality.

Researchers have addressed issues concerning caregivers of AD patients, and the different aspects of caregiving that may create stress, joy, a change in roles, or levels of intimacy, but have neglected to do the same for a marital relationship. Researchers have yet to gain insight into what happens in a relationship, from the couples' perspective, when AD becomes a factor. Wright (1991) did gather information about the marital relationship from both spouses; however, she only studied the couple together when looking at physical touch and affection. Although an individual person is afflicted by the symptoms of AD, the people related to that person also are faced with the difficulty of receiving an AD diagnosis. This would seem especially true in a marriage, in which a legal bond symbolizes the union of two people, suggesting that when something happens to one spouse, it happens to the other as well. Research is needed to describe how the relationship grows, modifies, and intensifies after one spouse has been diagnosed with AD, and as the disease continues to progress. How couples' perceive their relationship, and how that perception has been challenged or supported by the surrounding society also are important factors to consider when researching the marital relationship. This qualitative study explores how couples' make sense of an AD diagnosis from a biopsychosocial-spiritual perspective. Furthermore, the study is guided by the theoretical framework of social constructionism, as it best supports the aim of the study.

## **CHAPTER 3-METHODOLOGY**

Alzheimer's disease (AD) is a chronic illness that has risen significantly in prevalence over the past ten years and has the capacity to impact several domains of a person's life. In this study, the investigator explored how couples made sense of an AD diagnosis, by inquiring about the biological, psychological, social, and spiritual components of each couples lived experience. A social constructionist framework was used to understand how each couple made sense of an AD diagnosis by exploring the biological, psychological, social, and spiritual experiences that they have attached to the diagnosis process. A qualitative phenomenological study, embedded in a social constructionist theoretical framework, was chosen as the best fit for this particular study. The social constructionist framework allowed space for couples to define the important components of their individual experience. In addition, the biopsychosocial-spiritual perspective permitted each couple to reflect on several aspects of their experience, in a multi-faceted manner, instead of just exploring one piece of their experience, preventing opportunities for the couple to discuss other aspects of the experience that were significant for them. The research was analyzed according to a reflective phenomenological analysis strategy. In this chapter a thorough description of the study's methods have been provided along with the rationale for the design choices that were made throughout the process.

### **Qualitative Approach**

Qualitative research consists of the studied use and collection of various empirical materials for the purpose of describing moments and meanings in individuals' lives (Denzin & Lincoln, 2000). Qualitative is a term intended to emphasize the qualities, processes, and meanings that are not examined in terms of quantity, amount, intensity, or frequency (2000). Patton (2002) advised that it is best to let the research design emerge from the purpose of the study. A qualitative design and analysis were chosen as the most appropriate method for the purpose of understanding how couples make sense of an AD diagnosis. "Qualitative researchers stress the socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational constraints that shape inquiry" (Denzin & Lincoln, 2000,

p. 8). The investigator paid attention to all of these factors throughout the duration of the study, to stay grounded in the qualitative framework.

## **Research Design**

Creswell referred to the research design as “the entire process of research from conceptualizing a problem to writing the narrative not simply the methods, such as data collection, analysis, and report writing” (1998, p. 2-3). The research design of a qualitative study includes a compilation of design choices, often informed by a particular strategy of inquiry. Similarly, Denzin and Lincoln (2000) described the research design of a study as a flexible set of guidelines that connects theoretical paradigms to strategies of inquiry and data collection methods.

## ***Research Questions***

I set out to explore how different couples experienced the process of one spouse being diagnosed with AD from a biopsychosocial-spiritual perspective. The study was not intended to generalize what all couples experience, but to explore the AD diagnosis experience of the four couples interviewed and identify similarities and differences of the experiences of the four couples studied. The main research questions that guided the study were:

- *How do couples experience and make meaning of the process, prior to, during, and following one spouse being diagnosed with AD?*
- *What do married couples experience physically (signs, symptoms, behaviors) and medically (interaction with physicians, process of diagnosis, medications, exams) throughout the process of one spouse being diagnosed with AD?*
- *What do married couples experience mentally and emotionally throughout the process of one spouse being diagnosed with AD?*
- *What do married couples experience socially throughout the process of one spouse being diagnosed with AD?*
- *What roles do religion and/or spirituality have for couples' experiences of receiving a diagnosis of AD?*
- *What are some similarities and differences of how various couples experience the process of receiving an AD diagnosis?*



## *Sample*

According to the typology of sampling strategies in qualitative inquiry as outlined by Miles and Huberman (1994), a criterion-based sampling strategy was most appropriate for this phenomenological study. A criterion-based purposive strategy was appropriate since the researcher was gathering data on participants who have experienced the same phenomenon (Creswell, 1998). Therefore, because this study was focused on couples who have all experienced the same phenomenon, an AD diagnosis, all participants met the following criteria:

- 1) One of the spouses had received a formal AD diagnosis within the last 2 months.
- 2) The participant with AD must be identified by the referring physician as being in the mild or moderate stages of the disease and still able to provide informed consent.
- 3) The couple must have been married for 10 years or more, and
- 4) The couple must reside together.
- 5) Participants were English speaking.

Creswell (1998) stated that when conducting in-depth interviews lasting approximately one-two hours, seven subject units was a reasonable sample size. A phenomenological study must gather enough data to describe the meaning of a small number of participants who have experienced the same phenomenon. The sample goal in this particular study was seven couples. However, after nine months of recruitment, only four couples were recruited. Although more couples would likely have added to the data, I felt that the purposes of this particular research study were achieved with the four participating couples. The point of redundancy was not reached; however, several similarities and differences did emerge.

Participants were recruited from three separate sites at Nebraska Medical Center: a Geriatric Family Medicine Clinic, the Geriatric Assessment Clinic, and the Memory Disorders Clinic. Recruitment of participants began following the approval of the Institutional Review Boards (IRB) at both Nebraska Medical Center and Kansas State University. Once IRB approval was obtained, administrators and primary care physicians at Nebraska Medical Center involved in the diagnostic process of AD patients were contacted. The Geriatric Assessment Clinic and the Memory Disorders Clinic were added as referral sites six months into the recruitment process. A change of protocol was approved by the IRB at UNMC to formally approve this change. Each referring provider was provided with a brief description of the study to distribute to all potential participants that meet the criteria for the study's sample, see Appendix A to view the recruitment

flyer. The potential participants were given the option of either calling the primary researcher or giving permission for the researcher to contact them. One participant even requested information mailed to her first, than a phone conversation, prior to agreeing to the study.

Each participating couple was required to read and sign the informed consent, See Appendix B, explaining the potential risks and protections involved in the study. Each interview was audio-taped and video-taped (as for a back up method), then transcribed. Tapes of interviews were kept in a locked file cabinet. Each participant was given a pseudonym to protect his or her confidentiality throughout the write-up of the study.

### ***Data Collection Strategies***

The primary method of data collection for a phenomenological study is in-depth interviews (Creswell, 1998). The data were collected by conducting face-to-face, semi-structured interviews with each participating couple. Each interview took place in the couple's home per their request. Consistent with qualitative methodology, the assumption was made that the participating couples have perspectives that are "meaningful, knowable, and able to be made explicit" (Patton, 2002, p. 341). Each partner's perspective was taken into consideration as part of the couple construction of meaning.

### ***Question Formation***

Because of the exploratory purpose of this research, the interviews were approached with a general interview guide, developed to facilitate an open-ended, semi-structured interview process. According to Patton (2002), an interview guide will allow the researcher to approach the interview with a conversational style, yet with a set of focused topics to be addressed. The semi-structured interview guide was best suited for this research, given the population being interviewed. Some structure was needed to ensure that the investigator inquired about all four domains of experience, however; too much structure, such as a formal interview guide would have limited the flexibility of each couple's opportunity to share their unique experience. Because the couples included a cognitively impaired spouse, the ability to be flexible with the wording and sequence of the questions was necessary to help facilitate the interview process. The wording of the interview questions differed slightly depending on the participants' responses, as supported by the flexible nature of the semi-structured format in which the specific wording is not pre-determined (Merriam, 1998).

### ***Interview Questions.***

The interview questions served as a guideline for the interview process and were flexible so that the participants could lead the direction of the interview as they told their story. According to Patton's (2002) typology of question focus and tense, all questions were either focused on behaviors and experiences, or opinions and values. For example, questions inquired about symptoms, behaviors, experiences, values, and beliefs related to the disease process. This allowed the investigator to explore not only what was experienced, but how it was experienced. Interview questions inquired about a particular experience, AD diagnosis, and explored the meaning of that experience through the process of description (Creswell, 1998). Again, the wording and sequence of the questions varied slightly according to the participants and overall context of the interviews. All questions were asked, however, of all participants during the interview. Both spouses were allowed to respond to any question, but were not required to. The interview guide is presented below, but also is presented in Appendix C.

### ***Interview Guide.***

**Introductory questions:** The purpose of the introductory questions was to obtain some background and demographic information about the couples.

- How long have you been married?
- Is this your first marriage? When were you married previously?
- Do you have children? How many?
- What is your highest degree of education?
- What is (was) your occupation?
- How would you describe your relationship?

**Biological Questions:** The purpose of the biological questions was to explore the couples' understandings of the physical and medical aspects associated with the disease, as well as, their illness experience.

#### **Overarching Biological Question:**

- *What have you as a couple experienced physically (signs, symptoms, behaviors, etc.) and medically (interaction with physicians, process of diagnosis, medications, etc.) throughout the diagnosis process?*

- When did you each first notice signs or symptoms of the disease? What were they? What did you attribute them to?
- When did you first see a doctor about your symptoms?
- When were you first given a diagnosis of Alzheimer's disease? How were you told?
- How many medical opinions have you received?
- What is your understanding of what the disease is, including the cause, symptoms, and course of the disease?
- What has your experience with your medical providers been like?
- How do you feel your treatment of the disease been handled?
- Is there anything else that you view as an important component of your medical experience thus far?

**Psychological:** The purpose of the psychological questions was to explore the mental, emotional, and behavioral aspects that may have accompanied the disease, as well as, the couple's illness experience.

#### **Overarching Psychological Question:**

- *What have you experienced mentally and emotionally throughout the course of the disease?*
  - What thoughts, questions or concerns have you had following the onset of AD symptoms?
  - How would you describe your attitude and mood throughout the diagnosis process? How would you describe your spouse's attitude or mood?
  - What emotions/feelings have you experienced throughout the diagnosis process?
  - What have been the most emotionally challenging aspects of your illness experience?
  - What or who do you feel has made this process harder or easier for you as a couple?
  - How have you as a couple been able to get through this experience?

**Social:** The purpose of the social questions was to explore the relationships that have impacted or been impacted by the disease and the couple's illness experience (e.g. spouses, family, friends, children, parents, healthcare providers, etc.)

#### **Overarching Social Question:**

- *How have your social lives and relationships been impacted throughout the diagnosis process?*
  - How do you feel your marriage has been impacted throughout the course of the disease?

- What social support have you received throughout this process?
- How did your friends/family members react to your diagnosis?
- Did any of your relationships change (positively or negatively) following the onset of your AD symptoms? Which ones? How did they change?
- How have your family/friends showed you their care or concern during your illness experience?
- What types of support services were offered to you by healthcare providers?
- Were you pleased or disappointed with the amount and type of support you have received by friends, family, and healthcare providers? In what ways?

**Spiritual:** The purpose of the spiritual questions was to inquire about the beliefs and meanings that the couple has associated with the disease, including the role, if any, that religion or spirituality has had throughout the diagnosis process.

**Overarching Spiritual Question:**

- *What, religious, or spiritual experiences have accompanied the diagnosis process? How have these impacted your experience of receiving an AD diagnosis?*
1. What meaning has your experience with AD given to your life?
  2. What are your spiritual/religious beliefs as a couple?
  3. Have there been any changes to your spiritual, religious, or moral beliefs throughout the diagnosis experience?
  4. As a couple, what type of plan or approach have you come up with for dealing with the diagnosis process?
  5. How does this approach reflect on your philosophy of life as a couple?

**Closing questions:** The purpose of the closing questions was to wrap-up the interview and give the couple the opportunity to add anything that they feel is important?

- As a couple, what do you do together to cope with AD and everything that has come with it?
- As a couple, have you developed any new strengths or resources following the onset of AD?
- What is the single most important piece of advice you could offer to other couples going through the diagnosis process of AD?

- Is there anything else that has been an important part of your experience that you would like to add?

These interview questions were constructed according to the social constructionist framework, as an attempt to inquire about the biopsychosocial-spiritual experience of couples surrounding an AD diagnosis. Questions were open-ended to allow participants to share their experience and construct their own meaning attached to the AD. Responses to the questions were audio-taped and transcribed, then analyzed according to the strategy described below.

### ***Credibility of Researcher***

The researcher of a qualitative study is one of the major instruments of the design (Creswell, 1994). Accordingly, the researcher's ideas and understandings about the area of research help to establish the content of the questions and the basis for interpretation of the data. According to Patton (2002), any information about the researcher, whether personal or professional, that may influence data collection, analysis, or interpretation, should be reported. Harlene Anderson's (1996) belief is that social constructionism is more of a philosophy of life rather than a theory. Consequently, it is important to consider the researcher's ability to live the philosophy and underlying principles of social constructionism. Therefore, it was essential that both I and the co-interpreter, Dr. Jennie Buscher acknowledged our biases.

### ***Bias Statement of Primary Investigator***

As the researcher, I first identified my interest in AD while serving as domestic caregiver for a married woman with AD. I had the opportunity to visit this particular client three times a week for the duration of six months and witness her daily interactions, as well as her telephone conversations, with her husband. I observed the love between the two of them and witnessed their joys and struggles. This experience sparked my curiosity about their marital relationship. I was always drawn to the couple's interactions, in addition to the spouses' perceptions of their relationship, and the impact that AD had on their marriage. I personally believe that AD is a devastating disease that impacts the biological, psychological, social, and spiritual domains of a person's life.

I also think it is important to acknowledge my training in marriage and family therapy, because I will be exploring a marital relationship. I am strongly invested in fostering healthy relationships. I recognize that my training as a marriage and family therapist may influence how

I present the questions and how I interact with the participants. As the researcher, I will be part of the social construction of meaning as I create and facilitate the interview questions. I cannot just turn off my empathy for people, even when conducting research. Therefore, my empathic stance, could impact the project (e.g., responding to the participant's emotional responses throughout the interview). While my interests in AD and marital relationships are a significant part of me, I have acknowledged my biases and values that could affect my interpretations of the data yet will be conscious in bracketing out my biases as much as possible. Throughout my studies on families and relationships, it is my belief that when a family member is diagnosed with an illness, the family as a whole will undergo some tremendous changes that they may or may not be prepared to deal with. I often have thought that a marital relationship, in particular, would endure many changes that may be extremely tough at times, as well as extremely satisfying at times.

***Bias Statement of Co-Interpreter (Written by Dr. Jennie Buscher)***

As a Family Physician I work with men and women of all ages as they cope with any number of medical, social, and psychological challenges. I believe that when faced with challenging medical diagnoses, healthy relationships – whether between a husband and wife, parent and child, physician and patient, or between supportive friends – play a vital role in the coping and healing process. I understand the disease process of Alzheimer's disease and feel it is important in my own practice to work with husbands, wives, children and partners to encourage empathy and help them cope with the changes in their loved one. My background is in medical management and I have no formal training in cognitive therapy.

It is also important to recognize my research experience. I have a working knowledge of research methods, but my experience is primarily with quantitative data collection and analysis. Most of my medical training has placed emphasis on the value of quantitative research and although intellectually I find qualitative methods fascinating and useful, I recognize the biases inherent in my training that tend to dismiss the validity of qualitative methods. I acknowledge these biases and continually try to recognize how those biases affect my reading and interpretation of qualitative data.

## **Data Analysis**

Qualitative analysis presents the researcher with the great challenge of deciding how to make sense of a large amount of data (Patton, 2002). Since, the main focus of this study was to understand couples' experiences surrounding the diagnosis of AD, a phenomenological analysis strategy was appropriate for deriving themes from the interviews. Phenomenological analysis evolved through the methodology of reduction, the analysis of particular statements, and the search for possible meanings (Creswell, 1998). A co-interpreter, Dr. Jenni Buescher, engaged in the analysis process along side of the primary investigator to help reduce bias and increase the validity of the data. Dr. Buescher brought a different knowledge base and viewpoint to the study as a primary care physician with limited experience in qualitative data.

### ***Analysis Strategy***

The specific phenomenological analysis strategy chosen for interpreting the data in this study was developed by integrating strategies presented by Clark Moustakas and Bruce Douglass (1985) and Moustakas (1994). The approach is appropriate, because the steps emphasized the importance of the process and the researcher's role in that process. This approached a framework that informed the analysis process. The following steps were modified to understand the investigator's process of analyzing the data in a clearer manner.

### ***Analysis Instructions***

**Step 1) Epoche:** The process of the researcher examining his/her personal biases to become aware of prejudices, viewpoints, and assumptions regarding the phenomenon being studied. Moustakas (1994) further defined epoche as opening the research interview with an unbiased, but not uninformed, receptive presence. The investigators achieved the epoche process by being alert, looking with care, and attempting to see things the way they really were, or the way they were expressed by the participants. The following steps were completed to achieve the epoche process:

- a) Each investigator wrote a bias statement disclosing any past experiences, beliefs and biases relevant to the subject of this research.
- b) Each investigator kept a journal of personal thoughts, comments and insights throughout the analysis process and discussed these issues as they arose.
- c) Each investigator closed the epoche process by reflecting on her impression of the entire analysis process at the end of the study.



**Step 2) Phenomenological reduction:** This was the task of using textual language to describe just what the researcher sees. This was done by continuously going back and forth between looking at the transcriptions and describing them in textual ways that present varying intensities (i.e. fearful and courageous or angry and calm) (Moustakas, 1994). This involved the process of bracketing out the world and assumptions to identify data that are free of extraneous intrusions (Patton, 2002) then horizontalizing the data. The investigators completed step two by:

**a) Bracketing the Data:** The investigators bracketed out key phrases or statements that were related to the research questions and phenomenon being studying. All information outside of these brackets was set aside to focus on the essential information of the research study. Using the color identified for each category, after reading the transcript two times, each investigator highlighted the significant phrases or statements that they thought were significant to the experience of AD, and categorized them into one of the five domains:

Biological experiences: PURPLE

Psychological experiences: GREEN

Social experiences: PINK

Spiritual experiences: BLUE

Other experiences: ORANGE

After each investigator coded the data individually, they met to compare their identified significant statements and come to a mutual decision on what statements were significant and which domain they fit the “best”. Table 3.1 shows an example of a coded transcript with significant statements coded according to domain. The transcript in the table was the final coded transcript agreed upon by both coders.

**Table 3.1 Example from Coded Transcript of Case Three**

W: I get the salt instead of sugar.

H: I found that out as a child. I made peanut brittle one time and it looked lovely. It was beautiful and it looked like peanut brittle should be you know and when I measured out the ingredients, instead of sugar, I put in salt. It was really very salty. You have to have the right ingredients.

I: Any other emotionally hard parts for you?

H: Well, you wish you could improve her memory in some way but you can't. Some people have had yelling matches and so forth because so many doesn't remember things, you know. ...You hear people call one another stupid and everything else and it's not that. It's just that her memory is gone and you have to learn to accept that.

I: What or who do you feel has made this process harder or easier for you as a couple?

During the process of comparing coded transcripts, each investigator shared her reasoning, identified biases and questioned each other's reasoning until both agreed that all significant statements described an aspect of the phenomenon studied.

**b) Horizontalizing the Data:** This process involved spreading out the data for exploration, organizing the data into meaningful clusters, eliminating irrelevant, repetitive, or overlapping data, and identifying themes within the data. This was accomplished by treating every statement as having equal value and later eliminating statements that are irrelevant to the phenomenon and research questions. This left only horizons, which are the invariant constituents of the phenomenon, which are then clustered according to themes (Moustakas, 1994). To prepare for horizontalizing the data, the primary investigator compiled the significant statements in a chart according to category (See Table 3.2) below. The starting line number for each significant statement was also identified so that the investigators could refer back to the transcript if necessary for context. Each statement was cut out of the chart, resulting in small squares with one significant statement on each.

**Table 3.2 Example from Category Chart of Case Three**

<b>BIO</b>	<b>PSYCH</b>	<b>SOCIAL</b>	<b>SPIRITUAL</b>
W: You probably noticed it before I did. 122	H: Then I began to realize that she doesn't remember. Then you just have to accept it. 161	H: Yeah, we don't fight. You have to try to listen. 108	H: We've been pastoring churches for 44 years. 73
H: Since we have down here, we've noticed it more. 124.	H: I think it's hard for her to accept it. 162	H: You just have to adjust and realize that it takes two to fight and it takes two to get along. 113	W: Well I didn't preach...but I taught Sunday school... 79

Once the above table was cut out according to significant statements, the I:

1. Spread out the significant statements for each category.
2. Organized the data into meaningful clusters and labeled each theme. Each theme had to be mutually exclusive and represent a unique component of the phenomenon being studied.
3. Repetitive, overlapping, or insignificant data were eliminated.
4. After clusters, or meaning units were formed, both investigators met and reviewed the clusters to make sure that statements adequately portrayed the theme and that they retained their original meaning. Again, each investigator checked biases and questioned each other to make sure the themes reflected the couple's experiences as close as possible. The labels of each theme were questioned to make sure each investigator agreed that the label adequately represented the theme.
5. The primary investigator constructed a table of the final themes according to domain which presented descriptive examples for each theme. See Table 3.3 for an example of the final organization of themes and examples.

**Table 3.3 Example from Final Theme Chart of Case Three**

<b>BIOLOGICAL</b>	
<b>Cluster</b>	<b>Descriptive Examples</b>
<b>“I get the salt instead of the sugar”</b>	W: I get the salt instead of sugar. H: She began to repeat herself or ask questions and things. You’d tell her something and then she’d ask the same question again.
<b>Accommodating to Symptoms</b>	H: It just...she’s at a point that we need to work together so that if she wants to bake and she loves to bake.... H: She really shouldn’t go up those steps because she finds that hard enough... W: Somebody put that sign up there.
<b>PSYCHOLOGICAL</b>	
<b>Clusters</b>	<b>Descriptive Examples</b>
<b>Leaving Home</b>	H: One of the hardest parts, after I got out of the hospital, one son’s wife came up to help us...someone took us around to look at the facilities that we might possible be able to live in, assisted living, whatever, and to think about moving out. That was hard.
<b>“Appreciate what you do have.”</b>	W: Well, for one thing it helps you appreciate what you do have. Because in our case.....since we had the ministry at the nursing home for some time, but on the other hand, it’s kind of scary because we think well am I going to be there like them.

**Step 3) (Triangulation):** Moustakas (1994) described this as a reflective phase where many possibilities are examined and reflectively explicated. This process required the investigators to seek possible meanings through the use of imagination, varying frames of reference, employing polarities and reversals, and approaching the phenomenon from different perspectives. The clusters, or meaning units, were inspected for what they revealed about the essential, recurring features of the phenomenon.

**Step 4) Within-Case Summary:** This was the process when the researcher summarized each case and identified the underlying dynamics of the each couple’s experience through a process of imaginative variation, reflection, and analysis.

**Step 5) Cross-Case Analysis:** This was the final process which consisted of comparing and contrasting the results among cases to understand the overall themes that emerged from the data.

Both investigators completed this process together by searching for similarities and differences among the themes of each individual case.

- 1) Common themes among cases were identified and placed into a table with descriptive examples identified by case. Common themes were those that had similar themes and parallel themes were those that had not only similar themes, but similar descriptions of the themes.
- 2) Unique themes of each case were also identified and placed in a table.

The previous five steps included specifics of how the data were organized, analyzed, and synthesized. The above process of analyzing the interviews was adapted from the approach by Clark Moustakas and Bruce Douglass (1985) and Moustakas (1994). My own version of this analysis emerged throughout the process and was recorded in the steps above.

### ***Investigator Reflections***

In closure of the analysis process, the investigators circled back to the epoche phase of phenomenological analysis and reflected on the awareness of prejudices, viewpoints, and assumptions throughout the entire process. Following the completion of the analysis, each investigator summarized this process according to their individual impressions of the analysis process. This step was added to the methodology to help readers understand the dynamic process the investigator's experienced from start to finish.

### ***Primary Investigator Impressions***

Reflecting on the entire analysis process reminded me of the complex nature of qualitative research. It is so complex, that a 150 page paper does not come close to adequately describing the process. Although I have conducted qualitative research before, I was exposed to an entirely different experience while analyzing the results of this particular study. I often struggled with the jargon of qualitative research as I attempted to explain phenomenological analysis to a family physician. Prior to this experience, I did not feel experienced enough to stray and dare to create my own method of analysis. Nor do I now. However, I did learn the importance of adapting analytic strategies to work for the type of research and the investigator's involved in the research. I learned that there is value in letting part of the strategy emerge as the process unfolds. I also was impressed at the value of taking time to discuss, disagree, challenge,

and question your co-interpreter to enhance and strengthen the study, as well as the investigators' interpretations.

As the analysis process developed, I became aware of how different my experience was than the co-interpreter's experience, due to the fact that I was present during the interview and she was not. This distinction highlighted the amount of meaning that is constructed during the interview that cannot always be captured in a written verbatim transcription of the interview. I found myself catching my biases but also sharing with her important components that could not be seen on paper through our open discussions. I found myself getting excited as the analysis came to a close and common themes were emerging as recognized by both investigators.

Overall, I was struck by the depth and breadth of the experiences of these four couples. I was intrigued as I learned each couple's biopsychosocial-spiritual perspective. I found myself experiencing emotions of sadness and fear as I listened to the couples share their reactions and concerns. On the other hand, I also experienced emotions of hope and joy as I witnessed the partnership and faith that some of the couples displayed. I viewed this process as rich and of great value to enhancing my understanding as a person and medical family therapist, of what couples go through when one spouse has been diagnosed with AD.

### ***Co-Interpreter Impressions (Written by Dr. Jenni Buscher)***

As I try to write my impressions of this analysis process I am struck by how difficult it is to describe this experience. Primarily, I have learned a great deal about qualitative research. The inherent biases toward quantitative methods that I described in my bias statement ran deeper than I thought. I probably shouldn't be surprised that I hadn't been able to overcome the biases of the medical community as much as I had hoped. This role, however, helped me appreciate the challenges, limitations, and benefits of qualitative research methods in a way that my textbook learning never could.

As I think about the four interviews we analyzed, I am most struck by the way the qualitative methods helped us to break down each interview into useful parts. The methodology also helped us maintain an objective view on all of those individual parts and compare them to one another. Thus, the biases we developed as we went through each interview were exposed and disrupted when we compared all of the interviews to one another.

For example, as we were working through each interview, we would casually comment that this or that interview was similar to another one for whatever reason. I was convinced that

all four interviews were going to give us essentially the same information and that the differences among them were generally insignificant. As we looked through all of the individual case themes to compare the interviews to one another, however, I was struck by the themes that ended up being unique to each interview. There were several themes that were similar among all four couples, but the “leftover” themes reminded me of the distinctiveness of each of the couples. In the analysis of each individual transcript I had naturally remembered the common attributes and forgotten much of the uniqueness of each couple. The qualitative method, however, didn’t allow me to ignore what had been forgotten. The method itself helped ensure a complete analysis of the data.

On a more sober note, this project reminded me that AD stinks. The disease is confusing and frustrating and unpredictable. It is hard to know what is happening now, much less what is going to happen next. During this project I have had the opportunity to diagnose one of my patients with what is likely AD. She is still having a hard time understanding that the memory problems she is having aren’t really the same memory problems that other women her age are expected to have. Her daughter wants to help, but is walking that tightrope between protecting her mother’s dignity and protecting her mother from herself. Having the opportunity to hear these four couples explain their experience has helped and will help me as I face this diagnosis in my practice. In addition, hearing these couples reminisce about marriage, love and relationships has made me more cognizant of these things in my own marriage.

Overall, this project has reminded me that companionship is an important part of my patients’ lives. The diseases I diagnose in them will probably change their relationship with their companions forever. The more education, empathy and emotional support I can give them, the better off we will all be.

## **Verification**

### ***Determination of Substantive Significance***

According to Patton (2002), the findings of qualitative studies should have substantive significance, which can be determined by the following questions:

- 1) “How solid, coherent, and consistent is the evidence in support of the findings?”

(Patton, 2002, p. 467) The determination of solid, coherent, and consistent evidence

will depend on the use of ample participant quotes to support the key themes, or meanings.

- 2) “To what extent and in what ways do the findings increase and deepen understanding of the phenomenon studied?” (Patton, 2002, p. 467) The researcher should be able to clearly identify how the key themes enrich the understanding of the particular phenomenon being studied. The key themes should not overlap, should be clearly supported by direct quotes, and should be directly related to the phenomenon under exploration.
- 3) “To what extent are the findings consistent with other knowledge?” (Patton, 2002, p. 467)
- 4) “To what extent are the findings useful for some intended purpose?” (Patton, 2002, p. 467) The purpose of this study is not to make overarching conclusions, but to search for similarities and differences among the couples experiences. The findings should be consistent with the purpose of strengthening the understanding of how couples experience the diagnosis process of AD.

The investigators considered the previous questions consistently throughout the analysis process. Many times our meetings were focused on discussions related to the previous questions and significance of the findings.

### ***Standards of Quality and Verification***

The verifications and standards of phenomenological analysis are largely related to the interpretation made by the researcher (Creswell, 1998). Several different researchers have developed different criteria for judging the validity of a qualitative study (Dukes, 1984; Eisner, 1991; Giorgi, 1985; Lincoln & Guba, 1985; Moustakas, 1994); yet, the standards set forth by Polkinghorne (1989) were chosen for this particular study. Polkinghorne is one of several researchers who developed a standard of validity specifically for phenomenological analyses. He holds that a valid research study is one that is well grounded and well supported. More specifically, Polkinghorne recommended that researchers ask themselves five questions to establish validity in their study. Polkinghorne's questions are presented below, followed by a brief response of how the investigators' acknowledged these issues:



- 1) Did the interviewer influence the contents of the subjects' descriptions in such a way that the descriptions do not truly reflect the subjects' actual experience? *The interviewers frequently asked this question of themselves and of each other when interpreting the meaning of the transcripts. For example, comments such as, "Do you think that's what she meant? Here look at the context. I think she is saying...", or "How did you interpret that? It feels like we are forcing a meaning here."*
- 2) Is the transcription accurate, and does it convey the meaning of the oral presentation in the interview? *The primary investigator reviewed each transcript for accuracy, then shared the interview experience with the co-interpreter so that she could gain some understanding of the context in which the interview took place.*
- 3) In the analysis of the transcriptions, were there conclusions other than those offered by the researcher that could have been derived? Has the researcher identified these alternatives? *The investigators marked all significant statements even if they were not what we were expecting. The focus was on the unique experience of the couples, not searching for a specific answer.*
- 4) Is it possible to go from the general structural description to the transcriptions and to account for the specific contents and connections in the original examples of the experience? *Although a specific structural description was not written for each case, the case summary of each case is supported by the contents in each transcript.*
- 5) Is the structural description situation specific, or does it hold in general for the experience of all couples included in the study? *Each case had a unique description, in addition to a description of the common experiences among all interviews.*

### **Strengths and Limitations of Methodology**

All qualitative research encompasses "a complex, interconnected family of terms, concepts, and assumptions" (Denzin & Lincoln, 2003, 3). Merriam (1998) identified the main strength of qualitative research as being able to offer understanding of the chosen phenomenon from the participants' perspective, instead of from the researchers' perspectives. A phenomenological approach to research highlighted this strength by striving to understand how participants make meaning of their social world (Gubrium & Holstein, 2003). Another main strength of the study was that the couples had an opportunity to share their thoughts about the

AD diagnosis, and together construct a meaning surrounding that diagnosis. This might have enabled the couple to cope and adjust to the diagnosis together, rather than separately. Understanding how AD is a socially constructed phenomenon might help healthcare providers recognize when socially constructed meanings are prematurely guiding the experience of couples facing AD.

Limitations associated with the nature of qualitative research in general also are noted. The investigator in qualitative research is considered the main instrument in the study, and naturally brings his or her own values and beliefs regarding the phenomenon being studied (Creswell, 1994). Although verification methods were utilized to establish trustworthiness of the data, it is still subjective according to the investigator's own style of conducting the research. According to Denzin and Lincoln (2003), the relationship between investigator and participant, the situation, and the realities constructed by the participants and the researcher, shapes the investigation. Another limitation is tied to the emphasis of language in the social constructionist perspective. Language is how couples generate meaning with each other and for their relationship (Anderson, 1996). Beginning in the early stages of AD, individuals may experience symptoms of memory loss, confusion, and forgetfulness, which could affect their ability to communicate. It is important to consider that this restricted use of language might lead to a spouse being more likely to create meanings on behalf of his or her spouse with AD, thus being a limitation given the current research methodology.

## **CHAPTER 4-RESULTS**

The results of this exploratory, qualitative study illustrated the lived experience of four different couples, all of whom have recently experienced the diagnosis of Alzheimer's disease (AD) of one spouse in the marriage. Results of each within-case analysis will be presented in depth, followed by the results of the cross-case analysis. Included in each presentation of within-case analysis is background of the case, investigator impressions of the case, the main themes identified, and a comprehensive case summary. To provide a framework for understanding the results, a review of the research questions was provided below.

### **Review of Research Questions**

The research questions for this study were all intended to understand the experience of couples faced with a diagnosis of AD.

- How do couples experience and make meaning of the process, prior to, during, and following one spouse being diagnosed with AD?
- What do married couples experience physically (signs, symptoms, behaviors, etc.) and medically (interaction with physicians, process of diagnosis, medications, etc.) throughout the process of one spouse being diagnosed with AD?
- What do married couples experience mentally and emotionally throughout the process of one spouse being diagnosed with AD?
- What do married couples experience socially throughout the process of one spouse being diagnosed with AD?
- What roles do religion and/or spirituality have for couples' experiences of receiving a diagnosis of AD?
- What are some similarities and differences of how various couples experience the process of receiving an AD diagnosis?

The above research questions provided a guide for the study based on the biopsychosocial-spiritual framework. The identified research questions will provide readers with a foundation for the interpreting the results of the within-case analyses in the presented below.

## Within-Case Analyses

A within-case analysis was completed for all four interviews. Each transcript was analyzed according to the phenomenological analysis described in Chapter 3, then explained in a thorough write-up of each case’s results. The results of the within-case analysis consist of a background description of the couple, a representation of the my impressions of that interview, an in-depth description of the emerging themes descriptive of that couple’s experience, and a case summary of the each within-case analysis, an overview of the demographics of all the couples is presented to provide a context for the readers. To protect confidentiality, the names of healthcare providers will be represented by a blank line.

### *Overview of Demographics*

To provide a foundation for the within-case results, demographic tables were constructed to offer a background of each individual case. All demographics were based on participant report, except for the stage of AD which was determined by the referring physician, largely due to the MMSE score. The following two tables contain pseudonyms of the participants, identification of the participant diagnosed with AD and his or her severity of AD based on the Mini Mental Status Exam (MMSE), age, years married, rural or urban area, highest degree of education, occupation, and children. Of the participants with AD, two were female, two were male, two were in the early stages of AD, and two were in the middle stages of AD. Couples length of marriage ranged from 37 to 63 years, and participants ranged in age from 59 to 90 years old. Cases one and two are presented in Table 4.1, while cases three and four are presented in Table 4.2. An \* has been placed to identify the participant with AD.

**Table 0.1 Demographics of Case 1 and 2**

	Case 1		Case 2	
	M	F	M	F
<b>Pseudonym</b>	David*	Paula	Chris*	May
<b>Stage of AD</b>	Mild AD		Moderate AD	
<b>Age</b>	71	69	90	83
<b>Years Married</b>	49		63	
<b>Rural or Urban</b>	Urban		Urban	
<b>Highest Degree of Education</b>	Some College	High School Diploma	High School Diploma	9 <sup>th</sup> Grade
<b>Occupation</b>	Systems Analyst	Clerical Worker	Factory Worker	Factory Worker
<b>Children</b>	2 girls; 1 boy		4 boys	

**Table 0.2 Demographics of Case 3 and 4**

	Couple 3		Couple 4	
	M	F	M	F
<b>Pseudonym</b>	Steven	Beth*	Dean	Allison*
<b>Stage of AD</b>	Moderate AD		Mild AD	
<b>Age</b>	78	80	60	59
<b>Years Married</b>	57		37	
<b>Rural or Urban</b>	Urban		Rural	
<b>Highest Degree of Education</b>	High School Diploma	College Degree	Some College	Post Graduate Degree
<b>Occupation</b>	Pastor	Pastor's Wife	Construction Worker	Math Teacher
<b>Children</b>	3 girls; 3 boys		3 girls; 1 boy	

***Case One: David and Paula***

***Background***

David and Paula have been married for 49 years, with three adult children and six grandchildren. David described his main occupation as a “computer pioneer” with several different positions including: computer programmer, systems analyst, project leader and department manager. Paula has been doing clerical work since she graduated from high school at age 17. They described their marriage as “typical”, further explaining that they have had their share of fights, but overall have had a good marriage. Their marital history included moves across states, job changes, times of unemployment, raising kids with childhood illnesses, and now dealing with the diagnosis of AD. Less than two months prior to the interview, David was diagnosed as being in the early stages of AD, a diagnosis that he was shocked to receive. Out of a maximum possible score of 30, David’s Mini Mental Status Exam (MMSE) score was within the range of 25-30 at the time the interview took place. He was diagnosed after numerous doctor visits and extensive psychological testing.

***Investigator’s Impressions***

David and Paula were the first couple that I interviewed for this study. As I entered their quiet condo, I received a warm greeting from David as I waited for Paula to come out from the back bedroom. I was a little surprised that I did not recognize any symptoms of AD in David throughout the entire interview. I was struck by his awareness and curiosity of his own disease.

He seemed eager to learn everything he could about AD. Paula seemed much more reserved and reluctant than David. As the interview developed I began to understand my first impression of Paula as nervousness of answering questions and discussing something so personal and new with a complete stranger. As the interview progressed, I found myself recognizing how early David was into the disease process. Not surprisingly, David and Paula were actively constructing new meaning and making sense of the diagnosis of AD during the interview. They seemed to be grappling with accepting the progressive nature of the disease and beginning to worry about what the future may bring. I watched as tears came to Paula's eyes when she expressed her emotions surrounding the unknown of the future of her marriage. It seemed as though Paula and David were beginning to walk down an unknown path as they came to terms with David's disease merely months prior to their 50<sup>th</sup> Wedding Anniversary.

### ***Biological Themes***

As David and Paula shared their thoughts about the process of being diagnosed with AD, the following four themes emerged as being significant to their biological experience: 1) inability to recall, 2) experience of symptoms prior to diagnosis, 3) experience of diagnosis process, and 4) current experience of symptoms.

A significant theme that emerged as part of David and Paula's biological experience was the Inability to Recall. There was a clear emphasis on David's "inability to recall" information when describing his experience with the disease. David provided the following example of his inability to recall names:

*"But somebody that we had known for a long time, I'd call them Bob for 30 years and all of a sudden, I couldn't remember what their last name was and I would think and think and think and pretty soon, it would pop into my head or if it didn't, if you'd have taken and written ten names down on a piece of paper, I could have told you which one it was, so you know."*

Both interpreters became aware of this focus during the analytic process, but were unsure of its meaning at first. The inability to recall was reported by David as the primary symptom of his AD at the time of the interview. It was also the main reason why he wasn't convinced he had AD. David described this by stating, *"Ninety percent of my problem is I don't remember, but I know I'm going to go somewhere and I forgot it and she'll tell me and then I might forget it again."* David seemed baffled by having a diagnosis of AD when most of his symptoms had to do with his "inability to recall". This struck both the interpreters as an

illustration of David's desire to fully understand and make sense of the diagnosis of AD. *"I'll just...you know, things will blank out on me, but it's still...the majority of the problems I'm experiencing right now is recall."*

Another theme that helps illustrate David and Paula's biological experience is the experience prior to diagnosis. When reflecting on the first signs of AD, Paula stated that it was six years ago when she first started to worry about David. Paula described the first time she took David to the doctor regarding his symptoms, *"Well, we saw a doctor about five years ago or six years ago because I was worried about your memory and your depression."* David did not feel that his symptoms started this long ago, but listened as Paula shared her experience. Paula expressed frustration that she had a concern many years ago, but felt the doctors did not believe her. *"It's within six years ago. I mean, we went twice and they acted like it was kind of my hallucination that there was something wrong with him and they gave him a clear bill."* Following these initial experiences Paula said, *"And then gradually, I mean...I just accepted their word for it. So I just put it down to lack of attention until he was having anxiety and we went to Dr. \_\_\_\_\_ on February 19<sup>th</sup>."*

Experience of diagnosis process and current experience of symptoms also emerged as biological themes descriptive of David and Paula's experience. Experience of diagnosis process was identified as a significant theme because it illustrated how David and Paula viewed the process. David's diagnosis process consisted of seeing various providers and being evaluated in many different ways. David received a thorough examination by a geriatric physician who then referred David to a psychologist to be further evaluated. Paula explained, *"They asked us a lot of questions and everything and he told him he thought this was it, but then he sent him to a psychologist, Dr. \_\_\_\_\_."* David described his evaluating with the psychologist as "the long haul" where he all his tests on "numbers and words and all of that." After being referred from the geriatric physician to the psychologist, then back to the geriatric physician, David was told *"I think you're in the very early stages of Alzheimer's."*

He now describes his *current experience* of symptoms as "Right now, I can do anything I ever did but remember what I had for breakfast. Then again, it's mostly recall." As David stated, he is in the "pretty early stages" of AD. Other than the symptom of inability to recall, the only other symptom David has experienced is lack of appetite: "I don't know if I can blame

Alzheimer's, but I lost my appetite. I don't get hungry anymore." Paula agrees with this as she stated "He's got to put on weight, so I've been shoving everything in his mouth."

### ***Psychological Themes***

The psychological aspect of David and Paula's experience was portrayed by the following themes: attribution of symptoms, learning about AD, emotional experience, perception of coping, uncertainty about the future, taking it day by day, and making sense of the disease process.

As David and Paula told their story a theme emerged describing the various attributions David and Paula associated to David's symptoms at various points throughout the disease process. They shared their thoughts of what they were thinking might have been the cause of the symptoms as they arose. When David and Paula started to recognize David's memory impairment they had the following different ideas as to what the cause was:

*Paula: "Then it became pretty clear about a year ago that he was losing his memory, but I still thought it might be depression."*

*David: "I attributed it to the aging process. You get old, you get forgetful."*

Until they received a diagnosis of AD, Paula thought that it could have been depression, and David thought that it was just part of the normal aging process. David also explained why he thought it was not AD when he stated, "*The fact that most of the time what I could not bring up was there...I said well, that's not Alzheimer's. Alzheimer's goes away. You know, it's gone. You're never going to remember it. So when I went to see Dr. \_\_\_\_\_, I had convinced myself that it probably wasn't Alzheimer's for that very reason.*" The couple gave a snapshot of what was going through their minds when they recognized symptoms and what they attributed those symptoms to. Paula also explained that there are times when David does things that bothers her, but that she cannot distinguish whether they are related to the AD or not. She stated, "*You know I'll say something like that's a cute ad and he says 'What ad?' And he's laying on the couch and I'm sitting right there in her chair and he completely disappeared during the ad or something that he doesn't enjoy and it's like 'come back, come back'. And I don't really know what to blame it on, him or Alzheimer's.*" In the previous quote Paula illustrated the difficulty in knowing which behaviors were related to AD and which ones were not.

"*Honestly, we've cried.*" Paula stated, when explaining her feelings associated with her husband's diagnosis of AD. Emotional experience was a theme that emerged as David and Paula



shared their emotions and moods that accompanied the diagnosis process. The couple experienced a range of emotions including, shock, depression, fear, frustration and anger. David expressed his initial emotions in the following statements: *“Well, initially it hits you right between the eyes and you know, you don’t like to hear bad news.” “I took the test and everything and so most people, maybe it is a shock but with me, when he told me that it was, it was a shock.”* David expressed mainly shock when identifying his emotions related to the diagnosis, while Paula expressed more sadness and fear. When Paula was asked about her emotions surrounding the diagnosis she offered the following one word answer, *“Depressed.”* She continued to express her emotions as tears came to Paula’s eyes and she said, *“There are times when ...I mean I knew this was going to happen...[crying] Yeah, it is tough.”* At one point in the interview Paula looked directly at me and said, *“I’m scared.”* Paula summarized the couple’s emotional experience when she said, *“It’s been up and down since February 21<sup>st</sup>.”*

Although Paula and David expressed difficult emotions relating the diagnosis of AD, they both commented on their ability to handle the disease. The investigators identified this component of their experience as the theme Perception of Coping. After shedding a few tears, Paula identified her own strength by saying, *“Oh well, I’m a fighter.”* Interestingly, David seemed to have a different perception of their ability to cope when he replied, *“I suppose...I think I’m handling it really better than you do. The only thing that she has to cope with is me asking her questions about things that I should know, but you know, it’s affected our lives emotionally, but it hasn’t affected them...”* It seemed important to Paula that she viewed herself as strong and able to handle the situation. Paula further stated, *“I think we’re two very strong people to begin with.”* The investigators were curious about David’s statement of being able to deal with it better than she, and wondered if it was another aspect of his own process of coping.

Learning about AD and making sense of the disease process were two psychological themes that emerged as active processes of David’s experience. David expressed a strong desire to learn about his own disease. *“I have read books. I have been on-line. I’ve spent hours studying different articles and books on Alzheimer’s so that I could understand what I was looking at.”* The investigators interpreted this as a need to know as much as he can and find a rational explanation of the disease, which might have been a coping mechanism for David. He seemed to be interested in knowing what exactly the disease was and what he could expect as it progressed. An example of David’s search for clear information was portrayed as he stated, *“I can’t get it*

*because it varies apparently so much and I won't lie, but everything that I can determine from start to finish is different than what you read. I've read five to ten years....I've read five to fifteen years. I've read ten to twenty years.*" David was active in learning about the disease, but he was also trying to make sense of what he was learning and what was going on with him. Making sense of the disease process was a theme intended to capture the personal process David and Paula endured in order to make sense of the disease process. This theme illustrates the couples' understanding of AD, previous assumptions they had about the disease process, and their attempt to connect the literature to what they were actually experiencing. For example, David explained, *"I think we both have a pretty good understanding of that, that ...I mean that it is progressive, that there isn't a cure and that your mind...well I understand that what's really going on up there is the nerve cells are dying in your brain."* He acknowledged that he understood cognitively how AD impacts your brain. Paula illustrated the difference between what she thought would happen, and what actually is happening by stating, *"I really thought his memory would have gone fast."* David also explained, *"I think I'm pretty honest with myself when I look at things that are happening and I haven't seen a lot of things yet where the information is just flat gone."* These statements exemplify how the couple makes sense of David's disease in contrast to general information about the disease.

The last two psychological themes that emerged as David and Paula shared their experience were descriptive of their approach to dealing with the disease in the present and being uncertain of the future. Uncertainty of the disease demonstrated the reality that no matter how much David and Paula read, they would still not know exactly what to expect as the disease progressed. They expressed uncertainty of the progressive nature of the disease, financial burdens, caregiving roles, and even their upcoming marriage anniversary. David recognized the progressive nature of the disease when he explained, *"Especially when you know that it's going to be long and progressive and it's just going to get worse and worse and worse and worse over a long, long period of time. Emotionally that's tough to deal with."* Paula expresses her fear of taking care of David by stating, *"I'm watching this friend of ours and I'm petrified of what's going to come and I know it's going to come."* David also acknowledged the future burden on Paula as he stated, *"You know, I think we both know that if it ever gets that far, that it's going to be a lot tougher on her than it is on me."* David also shared the uncertainty of what future financial burdens may arise when he said, *"We've got our insurance. We're both on Medicare."*

*We've got our supplements and stuff like that, but beyond that, you know, I don't know what the financial burdens are going to be.*" Paula and David also considered their 50<sup>th</sup> anniversary when looking ahead as described by Paula, *"Looking ahead, thinking, you know...and our 50<sup>th</sup> anniversary and we want to go someplace and we want to...and I want to...I'm thinking...I'm waiting....is it going to be fine in a year from now?"* Uncertainty of the future can be summarized by Paula when she said, *"Anyway, this probably makes us look at the future more than what we might have looked at it differently and that's about it, I think."* In this theme, Paula and David acknowledge their understanding that the future would change, but that they were both uncertain as to how it would change. As uncertain as David and Paula were about the future, they managed to cope by living day by day. The last theme acknowledges David and Paula's attempt to worry less about what the future could be and try to focus on the present. David summarized this when he said, *"Right now, it's not causing a problem, you know, in our day-to-day living relationship or anything like that and you know, when it does, then we'll start worrying about that."* When Paula was asked what advice she would give to other couples she stated, *"I, at this point, would have no advice because I don't know what's going to happen."* David expressed that things are not bad today, but acknowledged that they would change when he stated, *"We haven't experienced the really bad things yet."*

### ***Social Themes***

Eight themes emerged as descriptive of the social aspect of David and Paula's experience. The following social themes were identified: role changes, marital impact: positive and negative, relationship with doctors, normalizing the experience, social activities, social relationship and support, previous exposure to AD, and the kids.

The themes that related directly to David and Paula's marital relationship were role changes, and marital impact: positive and negative. The theme of role changes was identified to demonstrate the shift in responsibility and caretaking in David and Paula's relationship. David called attention to the fact that he has been healthy most of his life, but that Paula is *"the one that will have to take this responsibility"*. This seemed to be unknown territory as Paula stated, *"But I've never ever had to take care of him...I mean like that and it's always been reversed, like you know, have babies and I mean my family...I've lost most of my family to cancer and so, you know, he's always been there for me. I just want to do it for him."* In the previous statement Paula expressed her desire to be able to return the favor of taking care of David. She stated, *"I*

*just worry that we're going to be able to get through it*", again calling attention to the unknown of the role shift that would take place. In addition to role changes, the theme of marital impact: positive and negative, is illustrative of the positive and negative ways that David and Paula's marriage has been impacted by the diagnosis of AD. Paula described the negative impact that AD symptoms were causing, prior to being aware of the disease. *"I thought it was because he didn't listen to me when I told him, you know...and I blamed and it caused arguments, not realizing that it was something else, but that was my biggest complaint."* When describing more of their marital dynamics Paula stated, *"He gets frustrated and he gets crabby and there are times that I get frustrated with him and I get angry and that's the only thing."* The couple also expressed empathy for each other. Paula stated, *"I do give him a bad time about forgetting."* David replied, *"I mean, I'm sure she gets tired of me asking her questions that I should know."* Although there has been a negative impact on David and Paula's marriage they also noted positive changes that occurred after David was diagnosed with AD. Paula expressed, *"We probably tell each other, we love you maybe a little bit more....maybe I appreciate him a little bit more than I was showing when he first retired."*

The couple's relationship with doctors seemed to be significant to their experience. Their relationship with the doctors that diagnosed David with AD was characterized by trust and respect. Paula stated, *"So, I really, really think highly of him."* David also acknowledged that he feels the doctors have done their job by stating, *"I mean they've done what they're supposed to do. I'm not unhappy in any way with any of the treatment I've received."* Paula summed up their experience with doctors by stating, *"I know that they certainly were more in tune with what was going on than the doctors we saw five years ago or four years ago."*

Relating to others and normalizing their experience seemed to be important to David. The following normalizing comments were made by David: *"I don't think that we are any different than anybody else that would have to go through it. It's probably difficult in any family when you get bad news about a relative."* David viewed his and Paula's experience as "normal". The researchers also interpreted David's normalizing of research and knowledge to help him calm his own worries of dying from the disease. He stated, *"I mean it's going to be a long time. I'm 71 years old and there are a number of things that can kill me before Alzheimer's."* *"There's...I can't remember the stats I read but something like fifty percent of the people with Alzheimer's*

*are going to die of something else. And you know, that's probably true.*" Although others may not understand, it was important for David to normalize his experience.

Social support, involvement, and influence were described by the following four themes: social activities, social relationships and support, previous exposure to AD, and the kids. Being able to still engage in social activities, such as golf for David and knitting for Paula was important for the couple. David expressed his physical ability to still do activities by stating, *"Physically I'm still great. I mean I play golf...."* David's ability to still play golf meant something else for Paula as she stated, *"I look forward to golf days because otherwise we're together 24/7. And I love him, but give me one day."* Paula highlighted the importance of her having some alone time. Although the couple was still involved in social activities Paula explained, *"We don't go out as much as we used to, so we spend a lot of time sitting there watching the idiot tube and you know."* The theme social relationships and support expanded on the social activities theme by addressing the amount of support they have and how it has been impacted. The couple explained that the people that do know about the disease "feel very badly" and offer to help. However Paula explained, *"Well to be honest with you, we haven't told a lot of people."* David explained not telling a lot of people by stating, *"People don't want to know it."* Even though they have not told many people Paula stated that people notice, when she said, *"Honey, when you repeat the same story a fifth time, they know something is wrong."* Another component of this theme was explained when Paula talked about being able to return support for her friend as explained in the following quote: *"That's the only thing that I can think will change, that I will return some of the stuff that I've been doing for Anne and the rest of us for the last three years, so...we're a pretty tight knit group."*

The theme previous exposure to AD was identified because of the focus that Paula and David put on watching a friend go through AD. The previous exposure to AD has helped the couple know a little of what to expect and have someone to relate to, but also has sparked worry about the future. Paula explained that she had a friend that could relate with her frustration with David's AD, as she stated, *"In fact, I have lunch with this girl, the one whose husband's family said he gets frustrated with John...did you at the beginning and she said, I still do. So I thought, that's pretty good. That's normal."* Learning that her friend has had similar reaction to her husband's AD seemed to help Paula to know that she was not the only one. On the flip side, she has seen the negative impact caring for a spouse with AD can have, as Paula stated, *"I'm*

*watching a very good friend hurting her own body by trying to take care of her husband and I know the things that she has to do.”* Being previously exposed to AD had seemed to help Paula and David prepare for what to expect, but also has heightened their worry of future changes.

The last theme that emerged as Paula and David shared their social experience was in relation to the kids. Paula was not sure how her kids would deal with the diagnosis as it progressed as she said that right now they were *“too busy with their own lives”*. Paula also implied that when she talks to her kids they try to tell her what they think she should do. She did not explain what this meant, but she did say that one of her daughters wanted them to get a second medical opinion. Paula’s response to her daughter’s request was *“If he wants to do that, it’s his choice.”* She further stated, *“I don’t talk about it with my kids anymore because they just say I’m too, you know, and so we just kind of ignore it.”* It seemed that Paula and David were in the middle of figuring out how to handle the disease and the input of their children.

### ***Spiritual Themes***

The three spiritual themes that emerged were pondering faith and death, believing and questioning God, and faith. David seemed to be pondering his beliefs about faith and death as he stated, *“I really don’t know if there’s a heaven and a hell. Or do you just die? Whether your soul lives after you’re dead, you know, I’m not saying that’s all hogwash. I’m just saying deep inside, I don’t know.”* Instead he stated his belief that *“whatever is going to happen is going to happen.”* He said, *“If there are any changes I can make now probably wouldn’t make any difference.”* The theme pondering faith and death is best explained by David stating, *“You know, I’ve heard stories about...there are people who find out they’re going to die, all of a sudden they get religion and whether that’s a play-it-safe mechanism or not, I have no idea.”* The word pondering was chosen because the investigators felt that David was actively processing his ideas of faith and death as he talked about them.

Believing and questioning God was a theme that was significant for Paula. She expressed this by saying, *“I know there’s a God. I don’t think He always listens.”* She explained that she *“totally believed”* that God saved one or two of her kids when they were little. However, she expressed her current relationship with God by stating, *“He’s certainly getting questions from me right now.”*

The spiritual theme that both David and Paula shared was faith. Although it was represented in different ways both David and Paula expressed having faith. David explains his

faith as being spiritual rather than religious. He stated, “*Well I believe there’s a higher power. I’m not sure. I can’t explain to you what that means to me.*” In this last quote he implied the personal nature of faith. When the investigator asked more about David’s faith he stated, “*I didn’t say I didn’t have any faith. There’s a difference between religion and faith.*” Paula described her faith as being something that she believes “*you need in your life.*” She specified her faith during this disease by stating, “*Uhm, I...during this particular disease, I think what I need to believe so that I can ask for support for me physically.*” Although when talking about religion and spirituality, Paula stated “*I believe in most of it*”, she also discussed having a need for it.

### **Case Summary**

David and Paula’s experience of being diagnosed with AD included biological, psychological, social, and spiritual components. However, of all the aspects of David and Paula’s experience, the majority of themes emerged from psychological and social domains. This makes sense when considering the structure of their interview. Throughout the interview, both David and Paula were actively processing the meaning of their experience. The interview served as a catalyst for meaning construction. There was an overall tone of Paula being worried about her ability to care for David throughout the course of his disease. The majority of Paula’s responses were focused on coping emotionally and physically with David’s diagnosis. Tears came to her eyes when she was asked about her emotional response and coping with the disease.

David, on the other hand, seemed actively focused on accepting and making rational sense of having AD. He seemed to gravitate towards finding reasons for his presentation of symptoms, and highlighting certain information that he had read about AD. David acknowledged that until recently he was in denial of having AD and did not believe that it was the correct diagnosis. Throughout the interview, David’s desire to have control and continue to function at his usual level emerged as an underlying structure of his experience. Paula often questioned him, when he made statements about being able to do everything he always could do, except for remember. Spirituality was central to Paula’s construction of meaning, but was not as important to David’s. David seemed to view spirituality from a pragmatic approach, as he questioned religion and life after death. He was curious about what would happen when he died, instead of knowing and believing in heaven, like Paula. Paula expressed faith despite her questioning God during this time. When discussing their spiritual meanings, Paula expressed some concern that

she did not know what would happen to David after death, since he did not believe in heaven. As individuals, David and Paula seemed to be constructing meaning in different ways and about different aspects of their experience. For example, David concentrated on his biological capabilities and impairments when making sense of the disease, while Paula put an emphasis on her emotional state and worry about the future. Overall, David and Paula's experience was characterized by an active search for meaning, and attempt to understand what the diagnosis means for the future of their marriage and lives together.

### ***Case Two: May and Chris***

#### ***Background***

May and Chris have been married for 63 years, longer than any of the other couples participating in this study. They have four sons together and have lived in the same house for most of their married lives. The couple met while doing factory work at a local plant. They described their marriage as being good, but having its ups and downs. Chris described that he started working as a common worker and worked into a foreman. May was a factory worker most of her life, explaining that she was always good with her hands. Chris was in the middle stages of AD when he received his first diagnosis at a family meeting at the Geriatric Assessment Clinic. At the time of the interview, his MMSE score was within the range of 15-20 out of a possible score of 30. During the interview, Chris did not remember being diagnosed with the disease, although May assured that he was present when he received the diagnosis.

#### ***Investigator's Impressions***

Chris was sleeping when I entered the house and I was greeted by May, a tiny older woman with a sincere smile. When I met Chris I had a gut feeling that this was a man that was happy to have a visitor, but had no idea what I was doing there. When I thanked the couple for letting me come to interview them I learned that my gut feeling was accurate. Chris said "*Oh, well sure...I don't know why you want to talk to us though.*" Not knowing exactly what Chris meant by that statement, I proceeded with the introduction to the study. I started to explain that I was going to ask the couple questions about their experience with AD, when Chris replied, "*I don't really understand. What disease? We don't have any.*" May glanced at me as I stared back with confusion until she said, "*He doesn't remember.*" I felt uncomfortable and awkward



throughout parts of the interview, and very comfortable during other parts. At times, Chris became distracted throughout the interview, inquiring about my handwriting and about my personal life, but he remained open and engaged throughout the entire interview. I was amazed at his ability to report details of his life over 50 years ago, but yet, not remember a diagnosis that he received a month ago. The interview was not eliminated because Chris was unaware of his disease. However, the interview was kept because it told a story...a very real story of how AD impacts the relationship of a couple that have been married for over 60 years.

### ***Biological Themes***

The four biological themes that emerged as May and Chris shared their experience of being diagnosed with Alzheimer's disease were knowledge of the disease, "He doesn't see it.", getting diagnosed, and recognizing something was wrong.

One of the most profound themes of May and Chris's experience was characterized by only two statements by May. 1) *"He doesn't see it in a lot of ways. He's not that far into it, you know. He's just on the start of it I think."* And, *"He doesn't understand a lot of what's going on and it's like I brought it on him and I have no...I don't know how to tell him, you know...it's just something that is happening with him."*

Although there were only two significant statements to support this theme, the investigators' selected it due to the theme being descriptive of the dynamic that May and Chris portrayed. This theme was descriptive of the biological impact the disease had on Chris's cognitive ability and May's firsthand experience of his repercussions of the AD symptoms. Another biological theme that emerged was the couple's knowledge of the disease. Although Chris didn't know he had the disease, he demonstrated basic knowledge of what the disease was when he responded to my question of what his understanding of the disease was by saying, *"loss of memory I guess."* May elaborated on his response by saying, *"That's what I would say, loss of memory and function I guess."* Both seemed to have a basic understanding of what AD was, even though Chris did not know it was a diagnosis he had received.

Recognizing something was wrong and getting diagnosed were the other two themes descriptive of the biological aspect of May and Chris's experience. Both of these themes were portrayed only by May. The theme of recognizing something was wrong describes May's experience of first noticing something was wrong with Chris. May started to notice symptoms about a year ago when Chris started repeated questions. She stated, *"He just didn't know where*

*he was at and stuff like that, you know...confusion.*” At first May thought Chris was just being ornery, but then she “could see it really wasn’t that.” She explained, *“That’s the thing that really ...that made me notice was...I was forever saying pay attention, pay attention, and he just couldn’t pay attention to a lot of things.”* The process of getting diagnosed began when May started discussing Chris’s symptoms with her own physician and had suspected he had it, but was not certain. She explained that Chris received the diagnosis of AD at a family meeting with the staff at the Geriatric Assessment Clinic. She said that Chris was present at the time of the diagnosis, even though he doesn’t remember it now. She explained that the doctors told her that *“he was in the first stages...and they wanted to help whatever way they could, with the medications and the different things to do.”*

### ***Psychological Themes***

Six main themes emerged as being significant to May and Chris’s psychological experience. All of the following themes were identified by the investigators as fitting best in the psychological domain; however, each theme also contained social implications as well. Frustration with AD symptoms was the psychological theme with the fewest supporting statements, but was still identified as significant because it described a specific emotion related to the AD symptoms. May described this frustration when explaining her sons’ response to their dad’s AD when she stated, *“See, that’s the one thing that the boys have all been so upset with him and he doesn’t want to pick up on some of that, so after a while it gets pretty annoying.”* Even though May and her sons know that their dad has AD they still get frustrated with his behaviors. *“See, that’s another thing, and that’s bothering him and then when we find a solution, then all at once, you don’t need it no more so you wonder, is that just an attention getter sometimes or is it just...what it is.”* Although May did not fully explain all of these thoughts, her frustration with figuring out AD symptoms was clear.

The four main emotions that May expressed as part of her experience with Chris’s AD were described by the following two themes: sadness and confusion, and feeling responsible and lonely. Sadness and confusion related to May *“not knowing what to do”* and stating very clearly, *“I just feel sad about it, you know?”* When I asked her what emotions come with the disease, she stated *“a lot of misery I think. It’s going to be a lot more.”* May further expressed her sadness by saying, *“I just feel sorry for myself I guess.”* In addition to feeling sad and confused, May felt responsible and lonely. The theme feeling responsible and lonely was best described by the

following statements, *“I feel kind of all alone in a way....and being so responsible until...I mean you can’t run to the phone all the time and ask somebody else what you should do yourself.”*

When interpreting this theme, I put it in the context of the 63 years that May and Chris had been married. When considering the context of spending more years of life together than apart, May’s next statement held more weight than if it stood alone. *“I can’t really talk it over with him cause it kind of goes over his head like it don’t mean anything to him, you know, so...I have to figure it out myself.”*

The psychological theme that was most descriptive of May’s approach to coping with Chris having AD was identified as the theme coping day by day. When asked how the couple copes with the AD, May stated, *“What do we do to cope with it? Like I say, day by day, whatever comes up.”* When looking at the other emotions that May was experiencing, being able to take things day by day seemed almost necessary. She further described this by saying, *“You just have to take it like they say, one day at a time, and it comes on so slowly that you don’t really realize it.”* In the previous quote, May called attention to the slow, progressive nature of AD and how she planned to deal with it. May summarized the theme coping day by day by saying, *“You just have to take it day by day I think, and whatever you think is going to work, that’s the way to go.”*

The last theme that was identified was the only theme that spoke purely to Chris’s experience, and had not just psychological, but biological and social implications. The theme “I didn’t know I had a problem” emerged in the beginning of the interview and continued to arise at various points throughout the interview. Chris looked at me with a perplexed gaze and said, *“In the first place, I didn’t know I had a problem. She says I do.”* Chris did recognize a problem, but attributing it to old age, as exemplified by the following examples:

*“You get to be 90....I don’t think you’re really sharp at everything...do you?”*

*“Yeah, but at our age don’t some people always have a lapse of memory?”*

According to the previous statements, Chris was aware of his memory problems, but did not know he had been diagnosed with AD. The component seemed unique and highly significant to May and Chris’s unique couple experience of AD.

### ***Social Themes***

The main social themes that emerged were *trying to help, trying not to be a burden, social support, questioning doctors, and marriage impact*. Trying to help, emerged as a theme

descriptive of May's efforts to help Chris when experiencing AD symptoms. May described her thoughts in the following statements.

*"He wants to do it himself. He's always been...he's done his own thing. But then there's certain things that he has a real hard time with, and then I'll say, well, let me help you, 'oh, I can do it myself'. Then I'm done. Do it yourself and when you need me, then you ask me, and I think that way, you know, he's not just becoming a cripple."*

May acknowledged that she may not always do the right thing, but that her intentions are to help Chris. May also expressed to Chris her desire for him to understand that she is trying to help him as she looked at him and stated, *"And try to understand that the one that doesn't have it is trying to help in every way they can and it isn't always the right way either, you know, cause you get upset."*

Another social theme that emerged was trying not to be a burden. May expressed her and Chris's effort to try to handle things themselves, without trying to burden their children. May stated, *"I don't want them to think they've got to be over here taking care of us."* In contrast to her previous statement, May also expressed being disappointed that her children have not helped more. She expressed, *"Well, I was disappointed in my own kids in a way that they haven't... well, one of them just had hip surgery, so he really couldn't be doing anything anyway."* There seemed to be an internal conflict between May wanting to be able to do it all herself and desiring some help. May reiterated, *"You know, I don't try to have them...we try to do things ourselves you know, but."*

Social support was a significant theme used to describe activities the couple participated in and the support of friends. Chris described his involvement in social activities when he stated, *"I play cribbage on Mondays, a bunch of us."* May explained that a lot of the people they had connections with have passed away, but that she and Chris still try to do things together. She illustrated this by stating, *"Well, we've lost so many of our friends you know. We used to play cards a lot and get together with a lot of different people and do a lot."* Although May expressed that they do not socialize as much as they used to, she and Chris still are very social, both with each other, and with others. *"But, we watch tennis together and I don't know a whole lot about tennis either, but baseball and some of that...soccer."*

As smaller theme that emerged as part of the social aspect of May and Chris's experience was that of questioning doctors. In this theme May expressed her concern at times as to whether

or not the doctors were doing the right things for Chris. When asked about their experience with their healthcare providers, May stated, *“Well at different times I wondered...well, whether we are getting the right medications and such, you know, from my doctors.”* May did not say anything in particular that she disliked about her providers, but instead expressed times which she has questioned what they did. May provided some reasoning for her questioning when she stated, *“And you know they’re not always right.”*

Marriage impact was the last social theme that emerged throughout the interview with May and Chris. This theme identified the impact AD has had on May and Chris’s marriage by describing the negative behaviors that have been present in the couple’s interactions following the diagnosis of AD. May stated that she gets bossy and that she *“yells more”* than she used to. Chris explained this trait in May by saying, *“She gets a little perturbed is all.”* May explained that she feels bossy because she has to preach to Chris and *“tell him what to do.”* After May stated that she gets bossy sometimes, her voice got quiet as she expressed another way her marriage has been impacted by saying, *“and not a partner to talk a lot of things over with, like you used to.”* As May stated, *“you just have to be patient with each other I guess.”*

### ***Spiritual Themes***

The spiritual aspects of May and Chris’ experience were conveyed by the following two themes: 1) values/way of life, and 2) affiliation with church. Chris expressed his spirituality by saying *“I helped everybody I can...been as helpful as you can get...what else can you do in life?”* May acknowledged that Chris always treated everyone well, and that his values/way of life was, in a way, his spirituality. The investigators included this as a theme because of the meaning that Chris constructed about his own spirituality and how he lived it daily. The other spiritual theme of affiliation with church, was purely descriptive of May and Chris’s portrayal of church. May explained that they do not go to church but stated, *“I like to watch a program on Sunday morning from Lincoln at that time that I enjoy.”* May explained that she used to be Catholic but that she let that slide. She currently described her spirituality and feelings about church as she stated, *“But we’re not real spiritual, you know. I wish we were more than what we are. We should go to church.”* It is uncertain as to whether May’s feeling that she “should go to church” was related to the AD or not. Either way, it seemed to be an important description of her own experience.

### ***Case Summary***

When interpreting May and Chris's overall experience, it is important to note that the majority of the emerging themes were supported primarily by May's responses, with the exception of the theme "I didn't know I had a problem.", which was solely based on Chris's experience. When reflecting on May and Chris's experience two competing themes help provide a structure for the essence of their experience: "He doesn't see it.", and "I didn't know I had a problem." Many of the other themes were tied to Chris lacking the awareness of having the disease. Bittersweet is the word that fits best with the experience May and Chris conveyed. Although, the interview was characterized by discomfort as Chris and May attempted to answer questions about a disease that Chris "didn't know" he had; there was an underlying sweetness about the couple. The sadness that May experienced when Chris didn't understand what was going on with himself was also experienced by the primary investigator. But it also was clear that May embraced every connection that she could with Chris. May felt alone, responsible, and weighted down by the AD. Another factor that shaped this couples experience was the age and general health of both May and Chris. As an 83 year old woman, May was not only concerned about Chris, but was also concerned about her own health problems and her ability to take care of Chris when her health was declining. This impacted the amount of burden she was feeling as Chris's caretaker. What readers were not able to see, were the emotions that were portrayed as May expressed her thoughts about the AD. As the primary investigator, when May looked me in the eyes and said "*I just feel sad, you know?*" I felt myself slump in my chair as I thought to myself "yeah, I know." Her smallest statements seemed to be packed full of emotion.

### ***Case Three: Steven and Beth***

#### ***Background***

Steven and Beth have been married for 57 years, 44 of which were spent preaching in churches together. Steven was the main pastor for various churches and Beth served along his side. Beth explained her position by saying "*Well, I didn't preach, but I taught Sunday school. At least in those days, the pastor's wife was supposed to do quite a bit of entertaining, you know...like when missionaries came or evangelists.*" Together they had three sons and three daughters, two of which were twins. They now have 18 grandchildren. They have moved several times for church, with the most recent being their current location. Steven described his marriage

to Beth as “*pretty good*”, followed by Beth saying “*Yeah, I guess it’s good. You know, if you last this long.*” They both emphasized the importance of listening to each other. Steven expressed that if couples want to get along, they can get along, but if they don’t they won’t last very long. Beth first saw a doctor three or four years ago when they noticed something was wrong. She was started on Aricept two years ago and diagnosed with Alzheimer’s disease just in the past month. Her MMSE score at the time of the interview was within the range of 15-20, out of a total score of 30.

### ***Investigator’s Impressions***

Steven and Beth were both very welcoming to have me in their home. Beth immediately stated that she was happy to do the interview with hopes that it might help somebody else. I was struck by Beth’s smile and contagious laughter, and Steven’s kind, soft-spoken voice. Within 10 minutes of the interview I had the impression of Steven and Beth’s marriage being characterized by respect and partnership. While Steven talked much more than Beth throughout the interview, when Beth had something to say he seemed to listen intently. The couple’s strong belief in God seemed to be the focus of not only their disease experience, but their lives in general. As I left the interview and reflected on the amount of awareness and insight that Beth had, I remembered her MMSE score of 19/30 and the duration of her symptoms. Her responses in the interview did not seem to fit her low MMSE.

### ***Biological Themes***

Four main themes emerged as being descriptive of the biological aspect of Steven and Beth’s experience of Beth being diagnosed with AD. The following themes explain the physical and medical aspects of Steven and Beth’s experience: “I get the salt instead of the sugar.”, accommodating to symptoms, getting diagnosed, and experience with medication.

“I get the salt instead of the sugar.” We agreed that this statement of Beth’s was a great example of the AD symptoms that she and Steven first noticed, and even fitting for the entire theme. In the interview Beth told Steven, “*You probably noticed before I did.*” Steven agreed and explained Beth’s first symptoms by stating, “*She began to repeat herself or ask questions and things. You’d tell her something and then she’d ask the same question again.*” As Beth and Steven continued to share their experience of recognizing AD symptoms, Steven offered me a cookie from a container sitting on the table. He then told me to be sure I didn’t eat the cookies on

the counter. Steven explained, “*Yeah. Try to...she has made cookies sometimes and they’ve been pretty runny and I haven’t been here. She likes to make cookies.*” Steven further stated that Beth still makes cookies but he has to be with her. “*How many times did you ask about, ‘did you have the egg in?’*” He demonstrated that Beth’s main symptom of AD was forgetting either things she just did or said.

The next theme, accommodating to symptoms, explained changes Beth and Steven have had to make to accommodate the symptoms of AD. Steven explained how he helps Beth bake by stating, “*It just...she’s at a point that we need to work together so that if she wants to bake and she loves to bake, so that she doesn’t get too much of one thing in and not enough of another. The telephone rings and she goes to answer and comes back...she has no idea what she’s done.*” Beth also explained other accommodations they have made to keep her safe when she pointed to the door and said, “*Somebody put that sign up there*”. The sign that said “STOP” was explained in the following way by Steven, “*She really shouldn’t go up those steps because she finds that hard enough to do.*” Steven and Beth seemed to accommodate the new needs of Beth in order to keep her safe from potentially harmful consequences of AD symptoms.

Getting diagnosed was a theme that briefly described Steven and Beth’s experience of the diagnosis process. Beth stated, “*I just don’t remember exactly when it was or how it was.*” Steven explained that they had both had an idea that it was AD before Beth received a formal diagnosis, as he stated, “*Well, I think we diagnosed before the doctor did.*” Steven and Beth started inquiring about Beth’s symptoms over four years ago, but did not receive a formal diagnosis until they went to the Geriatric Assessment Clinic specifically for an evaluation of AD. Steven explained that this visit was set after he was in the hospital for a while and their children were concerned about Beth’s safety. Steven stated, “*And from that point on, we decided that Mom can’t stay alone if I’m not there and so they decided to give her a thorough examination and everything.*”

Another component of Steven and Beth’s biological experience was described by the theme experience with medication. Prior to receiving a diagnosis Beth was prescribed Aricept to see if that would help her symptoms. Steven described when Beth first started medication, “*Well, we asked the doctor about it cause she was having...repeating herself so much. That’s why he asked questions. He didn’t think she was too bad. But, he recommended using 5 mg. of Aricept at first and then after about a year he went to 10 and I guess they’re trying other things too.*” David



shared his thoughts about the medication expressing that it *“hasn’t helped so far in improving things”*. Their experience with medication and the thoughts that come along with it seemed to be a descriptive component of Beth and Steven’s experience of the biological aspect of AD.

### ***Psychological Themes***

The following four psychologically focused themes emerged as significant to Steven and Beth’s experience, leaving home, “appreciate what you do have”, accepting the situation, and dealing with the diagnosis. Leaving home and “appreciate what you have” were two themes that emerged out of just one supporting statement. The investigators felt both of these were significant enough to stand alone as themes because they each described a unique and important aspect of Steven and Beth’s experience.

Leaving home explained a noteworthy aspect of Steven and Beth’s experience...they were moving out of their own home and into an assisted living facility. There was a for sale sign in their yard and they had already begun looking at various facilities. The following statement illustrated this theme, *“One of the hardest parts, after I got out of the hospital, one son’s wife came up to help us...someone took us around to look at the facilities that we might possibly be able to live in, assisted living, whatever, and to think about moving out. That was hard.”*

The theme “appreciate what you have” was described by Beth as she reflected on her experience with her ministry in nursing homes. She explained this by saying, *“Well, for one thing it helps you appreciate what you do have. Because in our case...since we had the ministry at the nursing home for some time, but on the other hand, it’s kind of scary because we think, ‘well, I’m going to be there like them.’”* Based on Beth’s experience with the nursing home ministry, she developed mixed feelings. She expressed that it helped her to appreciate the things that she has, but that it also scared her, since she knows that she and Steven are looking into assisted living facilities right now.

A significant theme that was very frequent as Beth and Steven shared their experience was accepting the situation. This not only was portrayed as a theme, but also seemed to be an underlying structure of Beth and Steven’s experience. This theme had various types of acceptance including, accepting the Bible, accepting loss of memory, accepting the progressive nature of the disease, accepting that Beth *“remembers all that she can.”* When specified what Beth was accepting she stated, *“Well, that it’s probably not going to get better. You know, I’ve had other things happen and they’ve gotten better.”* She acknowledged that AD was different

than other health problems she has previously experienced, due to its progressive nature, and accepted this. However, Steven shared the difficult nature of accepting this aspect of AD, by stating, *“I think it’s hard for her to accept it.”* He expressed, *“It just takes a while to adjust and be willing to accept things when you have to and just understand and also try to comfort as much as you can.”* Both Steven and Beth accepted the disease and all that comes with it, but recognized that accepting AD was not an easy task. He demonstrated that much of his ability to accept was grounded in his religious beliefs when he stated, *“Well, we just believe the Bible and we believe that the Bible is the word of God, and we’re willing to accept that.”*

The last psychologically focused theme, dealing with the diagnosis, is descriptive of how Steven and Beth have dealt with AD. *“Well, I wasn’t happy about it, but what can we do?”* This statement explained the realistic manner in which Beth approached the disease. As she stated, it did not make her happy, but she recognized that she had to accept it because there was nothing she could do about it. In contrast, she also expressed continued hope by stating, *“It hasn’t been too good, but I try to stay hopeful. I’m hopeful it will get better, but I have to accept that things are different.”* It is unknown whether she really believed things would get better, or if having some hope was just her way of dealing with the disease.

### ***Social Themes***

The social aspect of Beth and Steven’s experience seemed to be a significant component of their experience, as the following six themes emerged as important to understanding their experience: understanding and adjusting together, *“It’s best if I help her”*, community support, more time together, support from children, and reaching out to others.

The following three themes related directly to Beth and Steven’s relationship with one another: understanding and adjusting together, *“It’s best if I help her”* and, more time together. Understanding and adjusting together described the emphasis that Beth and Steven place of having to work together to understand each other and adjust to the disease. As Steven stated, *“We have to keep working together on things or else we may have problems.”* Beth expressed, *“I mean we have a little bit of understanding of the other person.”* Steven highlighted, *“You just have to adjust and realize that it takes two to fight and it takes two to get along.”* This theme identified that both Beth and Steven have chosen to work together on their marriage and actively try to understand each other. The theme, *“it’s best if I help her”*, was descriptive of the how the marital dynamics have changed a little between Beth and Steven. He explained, *“She still wants*

to do things. She doesn't want to just go lay down in bed and stay there the rest of her life. That's why she still wants to make cookies and stuff...I'll have to be by her side to see that she gets all the right ingredients in and doesn't get too much salt." He also expressed Beth's inability to remember things and how he tries to help by stating, "She doesn't want to hear it, or it's gone, or she's not going to remember it, and you just have to continue to do all you can to help". This theme was identified, because the help that Steven offered to Beth seemed to be a significant factor in shaping their experience.

The final social theme that related directly to their marriage was more time together. This theme stems from the other two themes since adjusting together and Steven helping Beth, as lead to the couple having more time together. Beth expressed, "We've had more time together." One way that the couple ensures that they spend time together is having a prayer routine. Steven explained this by saying, "Every day, we have time of prayer together." The couple explained that they have been doing this since before they were married. It seemed to be a very important tradition of their marriage that they have continued following the diagnosis of AD. Steven further explained how AD had impacted their marriage by stating, "I'd say it has made us closer". Beth replied, "Me too."

Two themes descriptive of Beth and Steven's experience speak directly to their experience of receiving support. Community support and support from children emerged as significant to understanding the social aspect Beth and Steven's experience. Community support referred to the support they received outside of their family support network. This included help that the couple received from organizations, such as Meals on Wheels and the Visiting Nurse's Association. Beth explained, "Well, we do Meals on Wheels but that's just Monday through Friday." After Steven recognized the support they receive from God, May added, "Oh, you know, I think it's important to have God's help and also not be too proud to accept other people's help." Other types of community support that the couple recognized consisted of interactions with other people and support from their church. Steven stated, "Well, we go to church in \_\_\_\_\_. The church family prays for us. We get over there every Tuesday night, we have prayers." This theme illustrated the wide variety of support that Beth and Steven receive from the community in which they live. The last social theme, support from children, was exclusive to their perception of the support they receive from their own children. Both Beth and Steven seemed to understand and believe that their children help them as much as they can. As

Beth stated, *“Well I think, you know, they’ve tried to be as helpful as they can. Maybe get through more phone calls and things like that.”* Steven gave a specific example of this type of support when he stated, *“We have three grandkids. Three of Molly’s kids came over yesterday to play games and stuff.”* His previous statement called attention to the emotional support that they receive, in addition to more instrumental kinds of support. Steven summarized their children’s support by saying, *“Oh I think they want to help as much as they can.”*

### ***Spiritual Themes***

Spirituality was a dominant part of Steven and Beth’s experience with AD, as demonstrated by the following four spiritual themes: relying on God, spiritual history, trusting in the Lord, and hope beyond this life. It is important to recognize that there are other aspects of this couple’s experience that fit under the spiritual domain, but that were described under another appropriate domain.

Relying on God was a theme that emerged to illustrate how Steven and Beth have relied on God to help them through this disease. As Steven expressed, *“We just continue to take it to God and pray more.”* The couple also explained that the experiences they have encountered in their lives have helped them feel closer to God. Steven explained that their close relationship with God has made it easier to cope with the disease. Another small spiritual theme was spiritual history. This theme was identified to call attention to this history that shaped Steven and Beth’s spirituality. Steven stated, *“We’ve been pastoring churches for 44 years.”* This seemed to be an important part of Steven and Beth’s spiritual background. Beth further explained her role by stating, *“Well, I didn’t preach...but I taught Sunday school. We had, at least in those days, the pastor’s wife was supposed to do quite a bit of entertaining, you know, like when missionaries came or evangelists.”* Since their history seemed such an important part of Steven and Beth’s relationship, the investigators viewed it also as an important theme.

Trusting in the Lord was a theme that emerged as being very important to Steven. Steven articulated, *“We were just coming to the point that God doesn’t heal everyone and we pray for her and we put things in God’s hands and we don’t worry that much about them. We’re going to trust the Lord and he’ll see us through all these things and if you have God to rely on, he helps so much through life.”* This theme was similar to that of relying on God, except for its unique focus on trusting the Lord to guide them throughout their life. It is important to note that some of the significant statements in this theme also fit in the psychological domain. To summarize the

message of this theme Steven stated, *“Thy will be done Lord. Give us wisdom. Give us your guidance.”*

### ***Case Summary***

Beth and Steven seemed to approach AD as “our disease” instead of Beth’s disease. Their experience was told in a way that illustrated their partnership with one another. They deferred to each other in the interview when appropriate and helped each other explain what they meant. Steven and Beth’s experience had an underlying tone of acceptance and adaptation to the way things were. They did not struggle with accepting the diagnosis and did not focus on the negative aspects of the disease. It was interesting that there were no negative emotions expressed, in relation to the diagnosis. Beth stated once, *“Well, it doesn’t make you happy. But I suppose it probably wasn’t terrible surprising because my mother had it, but you know, you just don’t always think it’s going to happen to you, but you know.”* This finding was intriguing given the couple’s strong religious foundation. They both relied heavily on their relationship with God to guide them through this process.

When asked about coping and adjusting to the disease, the couple referred to their relationship with God and trust that he would provide for them. Both investigators commented on the realistic and calm manner in which Steven and Beth handled the disease. The strength of Steven and Beth’s faith seemed to jump off the pages, as we read the transcript. Another significant feature of this interview was the level of insight that Beth portrayed. It did not seem consistent with her MMSE score and stage of AD. Some of the more in-depth and insightful comments about her own disease process came straight from Beth. She demonstrated an amount of awareness and insight that seemed unusual for her stage of AD. Overall, the couple seemed advanced in their process of making sense of the diagnosis of AD, even though, they were still actively adjusting to the disease as it continued to progress.

### ***Case Four: Allison and Dean***

#### ***Background***

Allison and Dean live in Allison’s childhood house, in a small rural area. They have been married 37 and have three daughters and one son. Dean works in construction and is out of town five days out of the week, and only home on weekends. Allison has a college degree in

Education, a Master's degree in counseling, and has been a math teacher for most of her career. Six months prior to the interview, Allison was forced to retire when symptoms of memory impairment started to affect her work. Her co-workers and boss encouraged Allison to get evaluated for AD. After going to a couple of local doctors, Allison and Dean traveled three hours to see a neurological specialist. At her visit with the specialist a little over a month ago, Allison was diagnosed with AD. Out of a total score of 30, her MMSE score was within the range of 20-25 at the time of the interview.

### ***Investigator's Impressions***

My first impression of Dean and Allison was how young they were to be facing a diagnosis of AD. Allison was 59 years old when she was diagnosed with AD. Allison and Dean had children that were younger than me! I felt sad for them. I was also surprised to find out that the school was the first to recognize Allison's symptoms, and that she was forced to retire shortly after. She learned that she had a progressive disease and would have to quit a career she loved at the same time. Throughout the interview Allison said very few words. She was very tearful and it seemed as though she had not even begun to make sense of her diagnosis and what it meant for her life. Although, the interview could have prompted the couples's ability to make sense of the diagnosis, it seemed very early in the process. There were points in the interview that I felt guilty for interviewing this couple about such a new and painful experience, when they had very little time to wrap their heads around it. However, this was the type of raw experience I hoped to capture when designing the study. I made sure that I did not push them to answer any questions and that I sat with their silence.

### ***Biological Themes***

The following five themes emerged as significant to the biological component of Dean and Allison's experience of the AD diagnosis: recognition of a problem, diagnosis process, self-recognition of symptoms, medication experience, and questioning doctors.

Two of the themes were small yet significant. Self-recognition of AD symptoms described Allison's recognition and description of her own symptoms. For example, Allison explained that "*There are times when I'm talking to a person or something and trying to think of a certain name, you know, something like that. I haven't done a lot of reading. I have some information.*" The investigator's included it because it described an important feature of her

experience even though it did not fit with any other statements. The other small biological theme was medication experience. This theme described Allison's experience with starting to take medication for the AD. She stated, *"Well, as far as taking the medications and things like that, that didn't bother me. It was good actually and I didn't have any side effects from one type of pill against the other..."* She expressed her willingness to try the medications and her experience with them so far.

Recognition of a problem is a theme that is illustrative of how Allison's symptoms of AD were first recognized. Allison explained how her symptoms were first recognized by stating, *"It was actually the school system is the ones that saw that there was a problem."* Dean agreed that the colleagues that Allison worked with were who first recognized her symptoms. Dean explained, *"They actually recommended that she go see a doctor and that what got the ball started and here we are now."* Allison explained a significant component of her experience being diagnosed with AD, when she said, *"Actually, that is the way that they thought it would be best...rather than to fire me was have me retire."* Allison was tearful as she explained that after the school recognized her symptoms, she was forced to retire, since her symptoms were affecting her job as a math teacher. Dean explained where he was when he heard this news as he stated, *"Actually I was over in \_\_\_\_\_ when I get the phone call that she is getting forced to retire."* How Allison was diagnosed was certainly a significant feature of her experience surrounding the diagnosis, since she was forced to retire from her life-long career due to the symptoms of the disease.

The last two themes descriptive of Allison's biological experience with the disease were the diagnosis process and questioning doctors. The diagnosis process for Allison and Dean started in the small town in which they live and ended in a city three hours away with a cutting-edge University Medical Center. Allison explained, *"Uhm, it was kind of hard for me to decide when exactly the diagnosis took place because I had been to so many places you know? But, I guess I thought that probably it was when we were at Dr. \_\_\_\_\_'s office that I thought well that must be the diagnosis, you know...I even went to my gynecologist."* Allison explained how she got referred to the medical center where she was diagnosed by stating, *"Somebody and my niece, was involved with clinical psychology and she arranged for a cat scan up in Norfolk with a clinical psychologist and so that was probably the next thing after...And then my oldest daughter Christine, arranged for the appointment with Dr. \_\_\_\_\_."* Allison was diagnosed

rather quickly, however; she still received numerous opinions. Questioning doctors was another theme that emerged as part of Allison and Dean's biological experience. Allison told Dean, "*I know that one time thought when we were down there...you were with me that time and you said, I don't think we'll do what he said...that was Dr. \_\_\_\_\_.*" Dean replied, "*Well that was because he wanted to put you on...he doesn't...His information was trial and error and he wanted to put her on some pills that I thought, well if we're going to an expert, you take the pills now and it may throw things off. So, that's why. Now that she's with an expert, she can do whatever.*" Dean explained that he wanted a specialist to look at Allison rather than just going to the family doctor in their small town. This seemed to be his way of making sure she was getting the best care possible.

### ***Psychological Themes***

The following psychological themes emerged as significant components of Allison and Dean's experience: past and present knowledge of AD, "Take it one day at a time.", disappointment, "I'm not the only one.", worries about the future, and emotions surrounding the experience. Past and present knowledge was a theme descriptive of the information that Dean and Allison had learned about AD, either recently or in the past. It described their knowledge that they each had retained about the disease. For example, Dean mentioned that he always used to relate AD with people who used aluminum cookware. Dean shared his past knowledge of the disease by stating, "*Somebody says you've got Alzheimer's, I don't even live with them, you know...cause back to the days, the aluminum cookware you know*". Allison explained that her understanding of the disease was based on her experience of her mother having the disease and recent information she had read. Allison questioned her understanding of the genetic aspect of the disease, "*My mother had Alzheimer's. So, it's genetic right?*" She also shared her knowledge of something she read when she stated, "*Well, I think somewhere in some of the information that I got, I read that it's a progressing disease.*" Both Allison and Dean had retained different information about the disease from different times and sources.

"Take it one day at a time." This theme was Dean's direct response to the question about how the couple had been able to get through this experience. He explained, "*Well for me, life is short, but you think it's long...but life is short and you've got to pay attention to what's going on in order to...you've just got to live your life no matter what happens, you know.*" His approach to



coping with his wife's AD was to take it just one day at a time. As Dean explained, *"The same thing doesn't happen every day."*

The theme disappointment emerged as Dean and Allison reflected on whether they had been pleased or disappointed with the support that they had received. Allison responded with, *"I haven't really been disappointed, yet."* In contrast Dean offered a very different response. He stated, *"Yeah, and sometimes I feel like I disappoint them more than they disappoint me. But yeah, it's not disappointing at all."* Dean did not elaborate on this response, but thought it explained an aspect of his personal experience throughout this process.

Similar to the theme of disappointment, the theme "I'm not the only one." described a specific aspect that helped understand Dean's experience. Dean found value in being able to share this experience with others. *"I mean I had to get it off my chest and I find out, 'well, I'm not the only one that's in this world that has that problem too.'"* He found out that he was not alone and that other people could relate to him. This normalized his experience and helped him to cope with his wife's diagnosis. He explained the value of this connection by stating, *"Yeah, and if it wouldn't have been for the people at work that I have conversations with all the time, I'd probably would be in the same boat as she's in right now."*

The other two psychological themes were worries about the future and emotions experienced. Dean and Allison shared their worries about the future as they discussed challenging aspects related to the disease. Since Dean currently is out of town during the week for work one of his concerns was expressed by stating, *"For me, am I going to have to stop working in order to take care of my wife?"* Similar to this concern Dean expressed worry about leaving Allison alone and making sure she is safe. He expressed,

*"To me, it's leaving her alone. Because like she says, her mother had it and I had to come over here and do things around the house to make them like child-proof, so that she wouldn't injure herself when her mother was alive and living here. I haven't done that yet to this house for her sake and that's one of the things that I'm concerned about."*

Dean expressed very real concerns about the future and knowing when to do things to help his wife stay safe. Besides being worried about the future, Dean and Allison experienced other emotions related to the diagnosis process. Allison expressed comfort in being able to be in the house she grew up in and the same small town she grew up in. She stated, *"It's been more comforting to be able to be here."* Dean shared difficult emotions that were related to his wife's

diagnosis. He expressed, “*Well, my attitude was upset. Not with her, but just upset period you know?*” Although the previous statement described Dean’s initial emotion when he learned about the disease, he also shared his emotional experience on a daily basis. Dean explained, “*Some days, it drags me down pretty hard and other days it doesn’t.*”

### ***Social Themes***

Themes that were descriptive of the social aspect of Dean and Allison’s experience were continued support and activities, small town, concern from family members, closer and better marriage, more time together, and previous exposure to AD.

Continued support and involvement was a theme that emerged as being a very significant component of Allison’s experience. In general, she stated, “*you know, like I said, being involved in the groups are good.*” She also described specific activities that she is still able to be involved with, such as, “*Well, I still am able to play the organ at church and that’s important.*” In addition to activities Allison engages in such as playing the organ and going to football games, she also described the emotional support she receives. Allison described, “*There’s lots of people. We have a...we have a prayer chain in the community so there’s about three people that started when somebody called and said we want her for so and so and then we called around so it gets around to everybody and we’re praying for that person, you know. And that’s one thing that I do. It’s called touching for people.* Again, being able to stay involved and receive support in her small community was very important to Allison.

The theme small town emerged as another significant aspect of Allison and Dean’s experience. Allison explained that she and Dean have always lived in the same town. They explained some of the characteristics of living in a small town. Dean stated,

“*Well I would say co-workers, even Allison’s co-workers, have made it easier because they talk about it all the time, wanting to know how she is. The harder ones...I don’t answer their questions. I just said, well didn’t you forget something once before? ‘Well, yeah, like yesterday.’ You answered your own question you know. In a community this size, everybody knows everything about you, so, before you know it.*”

They highlighted the pros and cons of living in a small town and other unique characteristics that come along with a small town community.

The theme concern from family *members* described a small group of statements that explained the concern Allison and Dean’s family members have expressed. Dean described the

concern from family members as he stated, *“The kids were very concerned. My immediate brothers and sisters were also concerned that it was related to...I mean the diagnosis you know. Everybody said there’s something wrong, but they just couldn’t put their finger on it.”* Dean acknowledged that family members were concerned even prior to the diagnosis. Allison gave a specific example of how her children and husband have showed their concern. *“I know we have one daughter. They called him and told him he should call me every day so that you know...and he does...almost every day and every night.”* As illustrated in the previous example, Allison’s daughter encouraged her dad to call Allison frequently while he was out of town to check on her, and that’s exactly what Dean did.

Two of the social themes both describe the impact that the diagnosis has had on Dean and Allison’s marriage. The themes a closer and better marriage and more time together, are both descriptive of positive changes that have occurred in Dean and Allison’s relationship. A closer and better marriage emerged from both Dean and Allison’s comments. Dave stated, *“Well, it’s probably brought me closer to her.”* Similarly, Allison expressed, *“Well I think it’s better, probably better.”* Dean also discussed that he has recently tried to get Allison more involved with helping out his mother, since she has macular degeneration. As a result, he expressed, *“Anne helps out in that aspect and we’re closer in that regard.”* Overall, they both felt that their marriage had been impacted in positive ways. A more specific way that Dean and Allison’s marriage was impacted is explained by the theme more time together. Dean is a construction worker, and prior to the diagnosis of AD, he explained that he and Allison had little time together. Dean stated, *“I want to spend more time with her now. It used to be I’d come home and throw my clothes on the floor and go downtown and spend it with the guys. Now, I still do it, but not as much downtown with the guys. I spend a little bit more time here.”* He also expressed trying to be around more and help Allison out as he stated, *“Now, instead of forcing her to cook, I cook or I take her out to eat, you know.”* The amount and type of time that Allison and Dean spend together is different than before she was diagnosed with the disease.

Previous exposure to AD is the last social theme that emerged from Allison and Dean’s experience. This theme was descriptive of the experience Dean and Allison had with AD prior to Allison’s diagnosis. The couple had a first-hand experience of the disease. Allison’s mom had AD. Allison described things that her dad did when her mom’s symptoms worsened. She stated, *“My dad was a lawyer, and I know there were things that he put somewhere and then they would*

*be put somewhere else, so my mom would change that or whatever so then he got so he found places to hide them, you know.” Allison also stated, “And I’m 59. And my mother was in the care home here in town for seven, seven and a half years before she died.”* These previous statements described Allison’s previous exposure to AD and how she makes sense of it now that she is going through it. Dean also expressed, *“Oh, my sisters keep sending...she’s a nurse, a registered nurse out of Washington and she works with hospice and she’s always sending information down the pipelines to us about it every now and then. She’s sent me two books that I know of and to my mother in that respect.”* Allison and Dean have been exposed to AD through witnessing it and through receiving more formal information about it.

### ***Spiritual Themes***

Two spiritual themes emerged as part of Allison and Dean’s experience. Keep the faith and spiritual identification were descriptive of Allison and Dean’s spiritual aspect related to the disease. The theme “Keep the faith.” came straight from Dean’s words. He stated, *“You’ve got to keep the faith. I mean, turn it over to the Lord and let Him carry it for a while you know? That’s the only way I can deal with it.”* This was a clear description of how important faith was to Dean and Allison. Allison also shared this belief and also said that she needed to *“keep the faith.”* The other spiritual theme, spiritual identification, was descriptive of how Allison identified her own spirituality. She stated simply, *“I’m pretty spiritual.”* She described her spiritual ties by stating, *“I go to another thing in town...is I go to the Share Group on Thursday morning and then they also have a Bible Study in the afternoon. Those kinds of things help a lot.”* Allison expressed her spirituality as helping her through this experience.

### ***Case Summary***

This case was surprising to the investigators during the analysis process. During the interview, I experienced the sadness and first-hand reaction of Allison’s new diagnosis of AD. However, when we read the transcript, both investigators commented that it seemed to have few very descriptive statements. When the transcripts were analyzed it seemed like little could be understood about Allison’s experience, since little was said. However, as the primary investigator, it seemed that more was said that day than any transcript could pick up. Allison’s lack of words were accompanied by looks that told more than words ever could, genuine tears, and moments that seemed to make her catch her breath, literally. This was illustrative of the

beginning process of constructing meaning of their experience and struggling to make sense of the diagnosis.

The difficulty Allison and Dean demonstrated in making sense of their experience was understandable, given that Allison was rather young to have a diagnosis of AD. Allison seemed to skim over certain questions as a coping mechanism. It was clear that it wasn't the AD that was preventing her from finding the words, but that it was the challenge of making sense of her world being flipped upside down in a matter of months. This interview likely brought up some important questions and concerns that Allison and Dean had not addressed yet. It also enabled them to share their experiences with one another and attempt to make sense of this experience as partners. Important underlying features of this case were the early age of diagnosis, the husband working out of town, and being forced to retire because of the disease. These three features influenced how Allison and Dean experienced the diagnosis of AD and the difficult emotions that the investigator witnessed during the interview.

### *Summary of Within-Case Analysis*

Each within-case analysis resulted in a rich description of how each couple experienced biological, psychological, social, and spiritual aspects of being diagnosed with AD. Themes from each individual case have been summarized in Table 4.3 according to biological, psychological, social, and spiritual domains. In Table 4.3, themes of each interview are listed side by side and categorized in one of the four domains. This table gives readers an understanding of the types of themes that emerged from each interview, and the domains that were most represented throughout the interviews. A review of this table will allow readers to view themes of each case side by side prior to presenting results from the cross-case analysis. The cross-case analysis demonstrated the similarities and differences among the experiences of the four couples who participated in the study.

**Table 4.3 Individual Case Themes**

	<b>Case 1</b>	<b>Case 2</b>	<b>Case 3</b>	<b>Case 4</b>
<b>Biological</b>	<ul style="list-style-type: none"> <li>• Inability to Recall</li> <li>• Experience of Symptoms Prior to Diagnosis</li> <li>• Experience of Diagnosis Process</li> <li>• Current Experience of Symptoms</li> </ul>	<ul style="list-style-type: none"> <li>• Knowledge of the Disease</li> <li>• “He doesn’t see it.”</li> <li>• Getting Diagnosed</li> <li>• Recognizing Something was Wrong</li> </ul>	<ul style="list-style-type: none"> <li>• “I get the salt instead of the sugar.”</li> <li>• Accommodating Symptoms</li> <li>• Getting Diagnosed</li> <li>• Experience with Medication</li> </ul>	<ul style="list-style-type: none"> <li>• Recognition of a Problem</li> <li>• Diagnosis Process</li> <li>• Self Recognition of Symptoms</li> <li>• Medication Experience</li> <li>• Questioning Doctors</li> </ul>
<b>Psych.</b>	<ul style="list-style-type: none"> <li>• Attribution of Symptoms</li> <li>• Learning about AD</li> <li>• Emotional Experience</li> <li>• Perception of Coping</li> <li>• Uncertainty about Future</li> <li>• Taking it Day by Day</li> <li>• Making Sense of the Disease Process</li> </ul>	<ul style="list-style-type: none"> <li>• Frustration with AD symptoms</li> <li>• Worry about Future Changes</li> <li>• Sadness and Confusion</li> <li>• Coping Day by Day</li> <li>• Feeling Responsible and Lonely</li> <li>• “I didn’t know I had a problem.”</li> </ul>	<ul style="list-style-type: none"> <li>• Leaving Home</li> <li>• “Appreciate what you do have.”</li> <li>• Accepting the Situation</li> <li>• Dealing with the Diagnosis</li> </ul>	<ul style="list-style-type: none"> <li>• Past and Present Knowledge of AD</li> <li>• “Take it one day at a time.”</li> <li>• Disappointment</li> <li>• “I’m not the only one.”</li> <li>• Worries About the Future</li> <li>• Emotions Experienced</li> </ul>
<b>Social</b>	<ul style="list-style-type: none"> <li>• Role Changes</li> <li>• Marital Impact: Positive and Negative</li> <li>• Relationship with Doctors</li> <li>• Normalizing the Experience</li> <li>• Social Activities</li> <li>• Social Relationships and Support</li> <li>• Previous Exposure to AD</li> <li>• The Kids</li> </ul>	<ul style="list-style-type: none"> <li>• Trying to Help</li> <li>• Social Support</li> <li>• Trying Not to be a Burden</li> <li>• Questioning Doctors</li> <li>• Negative Marriage Impact</li> </ul>	<ul style="list-style-type: none"> <li>• Understanding and Adjusting Together</li> <li>• “It’s best if I help her.”</li> <li>• Community Support</li> <li>• More Time Together</li> <li>• Support from Children</li> <li>• Reaching Out to Others</li> </ul>	<ul style="list-style-type: none"> <li>• Continued Support and Activities</li> <li>• Small Town</li> <li>• Concern from Family Members</li> <li>• Closer and Better Marriage</li> <li>• More Time Together</li> <li>• Previous Exposure to AD</li> </ul>
<b>Spiritual</b>	<ul style="list-style-type: none"> <li>• Pondering Faith and Death</li> <li>• Believing and Questioning God</li> <li>• Faith</li> </ul>	<ul style="list-style-type: none"> <li>• Values/Way of Life</li> <li>• Affiliation with Church</li> </ul>	<ul style="list-style-type: none"> <li>• Relying on God</li> <li>• Spiritual History</li> <li>• Trusting in the Lord</li> <li>• Hope Beyond this Life</li> </ul>	<ul style="list-style-type: none"> <li>• “Keep the faith.”</li> <li>• Spiritual Identification</li> </ul>

## **Cross-Case Analysis**

Once each case was analyzed individually, the investigators searched across cases for similarities, differences, and shared meanings. Similarities among cases were identified and differences were highlighted to acknowledge the unique features of each couple's experience. Possible shared meanings emerged, bringing the investigators closer to understanding how couples make sense of a diagnosis of AD. Results indicated that the process of meaning making depends on numerous different factors.

### ***Similarities***

Analysis across cases revealed 14 common themes that emerged across biological, psychological, social and spiritual domains (five biological, four psychological, four social and two spiritual). Of the 14 common themes that emerged, five were shared by all cases. The biological domain had the most commonalities among the four cases studied, with only one theme from each case being unique. The spiritual dimension had the fewest number of common themes, however; this dimension had the fewest themes overall. Common themes described the main experiences that couples shared, whereas, parallel themes were those in which similar features of the experience were shared across cases.

### ***Common Themes Shared by All Cases***

Five general themes were shared by every case in the study. However, each case had different descriptive characteristics of the "common theme". For example, each case had a theme that emerged about recognition of a problem, yet how the problem was recognized was different from case to case. The following three themes shared by all cases were biological in nature: recognizing a problem, experience of diagnosis process, and experience of symptoms. The other two themes shared by every case were social in nature: social activities and social support. More than one couple made sense of these themes as an important aspect of their experience, however; how each couple made sense of that aspect differed. Each common theme was described and made sense of below. Table 4.4 demonstrates the common themes found among cases, and provides a descriptive example from each case to exemplify the theme. Themes present among all cases are marked, as well as, themes demonstrating similar characteristics, otherwise described as parallel themes.

### ***Recognizing a Problem.***

Every couple expressed the process of first recognizing a problem and trying to make sense of what was wrong. Although every couple experienced a process of recognizing a problem, they each described it and made sense of it in a different way. For example, in cases one, two, and three either the spouse or the person with AD noticed a problem, whereas, in case four, the place where the person with AD worked first noticed a problem. In some cases, the problem was recognized when the person with AD was trying to do something, like baking, driving, or doing a cross word puzzle. The couple in case four portrayed a very different experience of recognizing a problem. Unlike the other couples who recognized a problem either with their spouse or themselves, the problem in case four was first recognized by colleagues of the individual with AD. This difference in the experiences yielded different ways of making sense of the disease. Whereas, the other couples were expecting something was wrong, couple four was informed of the recognition of the symptoms by someone else, leaving them shocked when the individual with AD was forced to retire and diagnosed with AD in the same month. Although recognition of a problem was identified primarily as a biological theme, it was connected to social and psychological aspects. Of the three couples that recognized the problem gradually in their spouse, negative emotions and social interactions were experienced prior to the diagnosis. The individual's memory impairment was misunderstood and perceived by the other spouse as purposeful lack of attention or not listening, thus having social and psychological implications. This highlights the systemic perspective that a change in one domain of experience influence changes in other domains as well.

### ***Experience of Diagnosis Process.***

A theme descriptive of the diagnosis process emerged in all four cases. Although each couple experienced a process regarding the diagnosis of AD, the characteristics of the diagnosis process differed from couple to couple. Each case received their first formal diagnosis from one of the following types of providers, whether by a geriatrician, a psychiatrist, a family doctor, or a social worker at a family meeting. Although each couple saw at least three doctors regarding symptoms prior to the diagnosis, it was clear that the diagnosis of AD can be given in many different ways. Three out of the four couples experienced a gradual process leading up to the diagnosis of Alzheimer's disease, characterized by uncertainty about the cause of symptoms, several visits to different doctors, and various medical examinations. In these cases, Cases #1-3,



symptoms began to appear years before the actual diagnosis was given. Case four differed in that, symptoms were recognized, several doctors were seen, and a diagnosis of AD was received all within the same three months. In Case four, the couple had little time to make sense of the symptoms, prior to receiving the diagnosis of AD. In this case, the couple also described their experience of living in a small town while going through the diagnosis experience.. They were told that the diagnosis was probably AD, but decided to drive three hours to see a specialist of neurological disorders to confirm the diagnosis. The other three couples had all suspected the diagnosis of AD prior to receiving a formal diagnosis. This might have led to a quicker adjustment to the diagnosis, but it also could have led to more angst related to the duration of experiencing symptoms with an unknown cause. It is important to recognize that for all couples, the recognition of symptoms in conjunction with the diagnosis process marked the beginning of their sense making process.

#### ***Experience of Symptoms.***

The experience of symptoms was explained by all couples in some way, shape, or form. Two of the individuals diagnosed with AD shared their own experience of their symptoms by providing examples of their own memory impairment. Only one individual demonstrated his symptoms during the interview by his lack of awareness of his own disease and inability to recall receiving a diagnosis. Three of the four spouses without AD, shared their experience of their spouse's symptoms, while one spouse acknowledged that he did not notice his spouse's symptoms until her colleagues at work urged her to see a doctor. He was not with her as much on a day to day basis. The most common symptoms experienced by the couples in this study were forgetfulness and inability to recall things that were previously well known, such as, directions and friends' names. Among almost all the cases, the spouses with the disease and the spouses without the disease experienced the symptoms differently. Case was the exception, since they both had a similar view on the symptoms.

#### ***Social Activities.***

All cases emphasized the desire and need to stay involved in various activities. The ability to stay involved in regular social activities seemed to hold significant meaning for individuals diagnosed with AD. It also seemed to be important that the spouse without the disease be able to continue their social activities as well. Some couples engaged in activities together, such as having dinner with friends, while other couples had more separate activities

such as playing cards with the guys or going to lunch with the girls. Two of the individuals with AD identified staying active as being especially important to their process of meaning construction. It seemed to give them a sense of identity to hold on to in the midst of experiencing a great amount of change and loss. One couple made an effort to go to church every week to have prayer with their friends. Although this was also part of their spiritual experience, it was an activity that they made sure they continued to be involved in every week. Other individuals spoke of activities as being an important part of helping them cope with the disease. For example, one participant expressed that continuing to play the organ at church was an important aspect of her coping with and dealing with the new diagnosis of AD. Although each couple highlighted the importance of social activities, the meaning of those activities was experienced differently from case to case.

### ***Social Support.***

Every couple in the study commented on social support as being an important aspect of their experience, even though the value, amount, and meaning of that support varied among cases. One couple explained that they had not told many of their friends about the disease, but that their friends suspected it. Therefore, since fewer of their friends knew about the disease, they had less support in coping with the AD. The two older couples both commented on having less social support than normal, since most of their friends were deceased already.

All of the couples identified their children as social support, even though some expressed that their children had not helped as much as they had hoped. Although the couples in this study acknowledged the need for help from friends and family, they also did not want to burden their loved ones. An important part of making sense of the experience for many couples was being able to view themselves as capable of taking care themselves and continuing to be independent. Two couples made sense of their children as helping as much as they could despite their busy schedules. Others made sense of support as being those organizations in the community, such as meals on wheels, and the visiting nurses association, that provided help for them in their homes. Three of the spouses without AD place meaning on having friends to talk to and share their experience with. Overall, social support influenced how the couples made sense of their experience in relationship to others.

### ***Parallel Themes***

The investigators classified parallel themes as those themes shared by two or more cases, representing strikingly similar characteristics. These were themes that not only highlighted the same general experience, but also had the same traits or meanings attached to those experiences. The following were characterized as parallel themes: experience of symptoms, worry about future, and day by day. Of all of the themes identified in this study, averaging 18 per case, only three had similar features and descriptions. This demonstrates that every couple experiences the diagnosis of AD in different ways. The reason the investigators added the parallel theme description, was to make a clear distinction between these few themes that have similar features and the common themes that just relate to the same general experience, as described in the previous section.

The theme experience of symptoms was not only representative of all four cases, but also illustrated striking similarities among all couples' experience of symptoms. All couples seemed to experience the beginning signs of AD in similar ways. In all cases, the individual with AD was experiencing forgetfulness that was out of character for them. They were forgetting how to do things that they had done for decades, such as baking, driving, or doing the crossword puzzle. They were unable to recall names of people or places that were always familiar to them. They were losing their train of thought and forgetting something that their spouse had just mentioned minutes ago. Although they might have showed up at different times, all couples reported experiencing the same symptoms of AD.

Three out of the four couples shared the theme worry about the future. This was identified as a parallel theme since the couples had similar worries and concerns about the future. Spouses without AD expressed a significant amount of worry about being able to take care of their spouse when the disease progressed and worsened. Most of them had known someone who had previously experienced AD and were aware of the severe complications that arose as the disease progressed. They were worried about how and when they would need to put in safeguards to protect their spouse, such as taking their license away, "child-proofing" the house, and having someone with their spouse 24/7. One man who worked out of town during the week, was concerned about if and when he would need to quit his job to take care of his wife. Couples were worried about their future living situation and financial concerns related to the care of the spouse with AD. Spouses with AD expressed worry about becoming too disabled and not being able to take care of themselves. They were also worried about the amount of responsibility their

spouse would have with trying to care for them. It was clear that all of the couples in the study worried about how their lives and relationships would change as the disease progressed. Even though couples were dealing with the AD now, they were all worried about the uncertainty of the future.

Day by Day was the last parallel theme that was identified across cases. During the analysis process, this theme stuck out to the investigators as a common approach for making sense of the AD. Case three, was the only couple who did not put an emphasis on taking things ‘day by day’. The other three cases all expressed the importance of taking things as they come and coping one day at a time. It was a way that the couples dealt with the overwhelming nature of the disease. As previously discussed, couples had so many worries about the future, that they could not possibly deal with them all now. This theme also acknowledged the couples’ understanding of the uncertain nature of the disease, recognizing that they had no idea or control over what tomorrow would bring. The table below summarizes the common and parallel themes identified across cases, prior to a discussion of the differences among cases.

**Table 4.4 Common Themes Among Cases**

Category	Theme	Exemplars
<b>Biological</b>	*Recognizing a Problem	C1-W: “Well, we saw a doctor Bowman about five years ago or six years ago because I was worried about your memory and your depression.” C2-W: “That’s the thing that really...that made me notice was...I was forever saying pay attention and he just couldn’t pay attention to a lot of things.” C3-H: “She began to repeat herself or ask questions and things. You’d tell her something and then she’d ask the same question again.” C4-H: “It was actually the school system is the ones that saw that there was a problem.”
	*Experience of Diagnosis Process	C1-H: “That’s where I took all my tests...numbers and words and all of that. He sent me there first and said he suspected it was and he sent me and I went through all the tests...” C2-W: “The first time that I was sure was down in Nebraska. My other doctor and I kind of suspected it back and forth but to really have a diagnosis...” C3-H: “Well, I think we diagnosed before the doctor did.” C4-W: “Uhm, it was kind of hard for me to decide when exactly the diagnosis took place, because I had been to so many places.”
	Knowledge of Disease	C1: “Well, I understand that what’s really going on up there is the nerve cells are dying in your brain.” C2-H: “Loss of memory I guess.” C4-W: “Well I think somewhere in some of the information that I got, I read that it is a progressing disease.”
	+*Experience	C1-H: “Right now, I can do anything that I ever did except remember

	of Symptoms	<p>what I had for breakfast. Then again, it's mostly recall."</p> <p>C2-W: "Even when he was driving or when somebody would say something to him and it would just go up and over his head..."</p> <p>C3-W: "I get the salt instead of the sugar."</p> <p>C4-W: "There are times when I'm talking to a person or something and trying to think of a certain name..."</p>
<b>Psychological</b>	+Worry About Future	<p>C1-W: "I'm watching this friend of ours and I'm petrified of what's going to come and I know it's going to come."</p> <p>C2-H: "Well, I don't want to be completely disabled, so I have to have somebody wait on me every time I turn around. What the heck. As long as I can do it, I'll do it."</p> <p>C4-H: "For me, am I going to have to stop working to take care of my wife?"</p>
	Experiencing Different Emotions	<p>C1-W: "Honestly we have cried."</p> <p>C2-W: "Confusion and such...not knowing what to do."</p> <p>C4-H: "Some days it drags me down pretty hard and other days it doesn't."</p>
	+Day by Day	<p>C1-H: "Right now it's not causing a problem, you know, in our day to day living relationship or anything like that and you know, when it does, then we'll start worrying about that."</p> <p>C2-W: "What do we do to cope with it? Like I say, day by day, whatever comes up."</p> <p>C4-H: "Take it one day at a time."</p>
<b>Social</b>	*Social Support	<p>C1-W: "Somebody that you can talk to is important."</p> <p>C2- "Well, the social worker said something about maybe getting together with other people that have the same problems, you know, organizations..."</p> <p>C3-W: "Well, I think you know, they've tried to be as helpful as they can. Maybe get through more phone calls and things like that."</p> <p>C4-W: "We have a prayer chain in the community so there are about three people that started when somebody called and said we want her for so and so and then we called around so it gets around so it gets around to everybody and we're praying for that person, you know, and that one thing that I do.</p>
	*Social Activities	<p>C1-W: "I mean, we have a regular place where we go and have drinks and stuff and party with friends..."</p> <p>C2-H: "I play cribbage on Mondays."</p> <p>C3-W: "I know I'm not out as much as I used to be, but I still see a fair number of people."</p> <p>C4-W: "Well, I am still able to play the organ at church and that helps."</p>
	Positive Marital Impact	<p>C1-W: "Other than that, I think it impacted our marriage. We probably tell each other I love you maybe a little bit more."</p> <p>C3-W: "Well for one thing, we have more time together."</p> <p>C4-H: "Well, it's probably brought me closer to her."</p>
	Making Adjustments	<p>C1-H: "But she's the one that will have to take this responsibility."</p> <p>C3-H: "You just have to adjust and realize that it takes two to fight and two to get along."</p> <p>C4-H: "Now instead of forcing her to cook, I cook or take her to eat, you know."</p>

	Previous Exposure to AD	C1-W: "I'm watching a very good friend hurting her own body by trying to take care of her husband and I know the things she has to do..." C4-H: "Somebody says you've got Alzheimer's, I go I don't even live with them, you know...cause back to the days, the aluminum cookware, you know..."
<b>Spiritual</b>	Faith	C1-H: "I didn't say I didn't have any faith...there's a difference between religion and faith." C4-H: "You've got to keep the faith."
	Belief and Trust in God	C1-W: "I know there's a God." C3-H: "We're going to trust the Lord and He'll see us through all these things."

\*Themes present in all cases.

+Themes identified as parallel.

### *Differences*

Although similarities among cases emerged, there were still many differences among each couple's experience. Unique themes were those identified as being exclusive to one particular couple's experience. Table 4.5 displays the unique themes for each case. While conducting the cross-case analysis, the investigators struggled with whether or not these unique themes were significant or not. After numerous discussions about the relevance of these themes, it was determined that the unique themes of each case were significant because that couple identified them as an important aspect of their unique experience. These unique themes, as depicted in Table 4.5, were the elements that made each couple's experience unique and meaningful to them.

While comparing the cases with one another, several differences emerged. Each case had a unique tone and focus to that couple's experience. Case one was focused on actively understanding and making sense of the disease. Case two was focused on expressing the challenges and worries associated with the experience. Case three was focused on accepting the situation and appreciated what they did have. And, case four was focused on coming to terms with the disease and beginning to make sense of it. Compared to the other cases, case four had the least amount of content and unique themes. This may be the result of the great amount of change that the couple had endured in the least amount of time, compared to other couples.

It was interesting to look at the unique themes from cases two and three side by side, since these cases represented the two participants of the study with the greatest severity of AD. Although the individuals with AD in cases two and three, were both in the moderate stages of

AD, Case three portrayed the most difficult and challenging experience, while case four portrayed the most positive experience of all cases. Case three represented the only individual that could not remember he had been diagnosed with AD. Not surprisingly, this was the case in which the spouse without AD expressed the most responsibility and burden related to her caretaking role

The psychological findings of case three were unique and did not compare to any other interview. There was a realistic and positive focus on their experience, represented by appreciation and acceptance. Case three was also the only interview that discussed the importance of giving support to others in addition to receiving it. This was also the interview in which the person had a stage of AD that was incongruent with the level of insight and awareness displayed during the interview. We were curious as to whether the positive nature of their experience was at all related to their spiritual beliefs and practices.

When reviewing the unique features of each case, the psychological and social domains of experience illustrated the greatest amount of variability. The biological domain showed the least amount of variability among cases and the greatest amount of similarities. It is not surprising that the couples' physical experiences were fairly similar, yet how they made sense of their experience mentally, emotionally, and socially was very different. This highlighted the complexity of couples' sense making of an AD diagnosis experience.

**Table 4.5 Unique Themes**

<b>Category</b>	<b>Case 1</b>	<b>Case 2</b>	<b>Case 3</b>	<b>Case 4</b>
<b>Biological Themes</b>	Inability to Recall	"He doesn't see it."	Accommodating to Symptoms	Self Recognition of AD Symptoms
<b>Psychological Themes</b>	Attribution of Symptoms	Frustration with AD Symptoms	Leaving Home	Disappointment
	Learning about AD	Feeling Responsible and Lonely	"Appreciate what you do have."	
	Perception of Coping	"I didn't know I had a problem."	Accepting the Situation	
	Making Sense of the Disease Process		Dealing with the Diagnosis	
<b>Social Themes</b>	Role Changes	Trying to Help	Understanding and Adjusting Together	Small Town
	Relationship with Doctors	Trying not to be Burden	"It's best if I help her."	Concern from Family Members
	The Kids	Negative Marriage Impact	Reaching out to Others	
<b>Spiritual</b>	Pondering Faith	Values/Way of Life	Relying on God	

<b>Themes</b>	and Death			
	Believing and Questioning God		Hope Beyond this Life	

### **Summary**

The results of this phenomenological analysis illustrated how four different couples experienced and made sense of the process of one spouse being diagnosis with AD. Each couple shared their experiences of the diagnosis process among the following four domains of experience: biological, psychological, social, and spiritual. Themes emerged as being significant to each couples’ unique experience, and common themes emerged as significant across all cases.

A description of each couples’ experience was provided and explained according to the biopsychosocial-spiritual perspective. A case summary synthesized the overall experience of each couple, highlighting the unique aspects of that case. Following results of the within-case analyses, results from the cross-case analysis were explained. The cross-case analysis resulted in common themes, parallel themes, and unique themes. Similarities and differences emerged across cases to make sense of the overall experience of the couples in this study.



## **CHAPTER 5-DISCUSSION**

In this chapter, a thorough discussion is provided about the implications of the findings regarding couples' experiences of the diagnosis of AD, as presented in the previous chapter. An overview of the study is included first to remind readers of the background, purpose, and summary of findings for this particular study. Following the study overview, a discussion is provided about the inferences that were deduced from the findings. This discussion will help readers understand how couples experience and make sense of an AD diagnosis. Similarities and differences between the present study and previous literature will be highlighted throughout the discussion of the findings. The unique contributions of this study are also discussed, as well as, the strengths and limitations of the study. Furthermore, future implications and suggestions for clinicians and researchers will be addressed to conclude the discussion of findings.

### **Overview of Study**

This qualitative study explored how four couples experienced and made sense of the diagnosis of Alzheimer's disease from a biopsychosocial-spiritual perspective. Each couple was interviewed conjointly in their homes and was asked about the following four different aspects of their experience of being diagnosed with AD: 1) biological (physical and medical aspects), 2) psychological (mental, emotional, and behavioral aspects), 3) social (relationship aspects), and 3) spiritual (aspects related to beliefs, morals, or values). Interviews ranged from 60 to 90 minutes long and were audio-taped for transcription purposes. Each transcript was analyzed individually to identify themes specific to each case. Then, results across transcripts were analyzed to identify similarities and differences among the experiences of all cases studied. Results consisted of a set of themes organized by domain (biological, psychological, social, or spiritual) for each specific case. Results of the cross-case analysis revealed 14 common themes, three parallel themes, and 32 unique themes. Shared meanings emerged from the couples' experiences and offered a glimpse into the process of making sense of a diagnosis of AD.

### ***Purpose***

The purpose of the study was to gain a systemic understanding of how couples experience the diagnosis of AD from a biopsychosocial-spiritual perspective. More specifically, the investigator hoped to capture a snapshot of what couples experience shortly after one spouse has been diagnosed with AD. A social constructionist framework was used in conjunction with the biopsychosocial-spiritual model, to explore the biological, psychological, social, and spiritual factors which inform and possibly influence couples' experiences in relation to an AD diagnosis.

### ***Summary of Findings***

The findings of this study included unique descriptions for each couple's case and a composite description of the cross-case analysis, highlighting similarities and differences among cases. The biopsychosocial-spiritual model was a significant tool in eliciting a systemic understanding of each couple's experience, and exposing unique aspects of couples' experiences. Analysis across cases revealed 14 common themes that emerged across biological, psychological, social and spiritual domains (five biological, four psychological, four social and two spiritual). The following five themes were shared by all cases involved in the study: recognizing a problem, experience of diagnosis process, experience of symptoms, social support, and social activities. Parallel themes were identified to highlight those themes across cases which spoke to the same process, but also shared similar characteristics of that process. Although 14 common themes emerged, the following three were the only ones identified as parallel themes: experience of symptoms, worry about future, and day by day. The overall analysis illustrated many more similarity among biological experiences than any other domain of experience. Although each case had unique features, Case three stood out as having a completely unique psychological experience, as well as, a significant spiritual foundation. Overall, this study emphasized the importance of using a systemic framework, such as the biopsychosocial-spiritual model, to gain a rich, in-depth understanding of how different couples experience the diagnosis process of AD.

### ***Discussion of Findings***

The following discussion of findings explains the relevance of the findings in regards to understanding how couples make sense of an AD diagnosis. First, an explanation of what the findings reveal about the process of meaning construction is provided in conjunction with the

supporting findings from other studies. Then, the unique contributions of this study will be discussed.

### ***Social Construction of Meaning***

Although the results of the study are not generalizable to all couples experiencing AD, due to the sample size, the results do offer some insight into understanding how couples make sense of the diagnosis of AD. Based on the phenomenological findings of this study, five tentative inferences were made about how couples experience and make sense of an AD diagnosis.

- 1) Couple's sense making of an AD diagnosis is a gradual process that is constantly evolving.
- 2) Couples make sense of a diagnosis of AD based on the interplay of biological, psychological, social, and spiritual experiences.
- 3) Meaning is constructed one day at a time.
- 4) Making sense of a diagnosis of AD in the context of a couple's relationships is often embedded with worries about the future primarily due to the progressive, debilitating nature of the disease.
- 5) Couples' social context is an important factor in adjusting, coping, and making sense of the AD diagnosis.

### ***Making Sense of AD is a Gradual Process***

For the couples in this study, making sense of the diagnosis of AD was a dynamic process often characterized by questioning, denying, adjusting, and accepting. The process of meaning making often began when symptoms were first noticed and continued to evolve as the disease progressed and the couples sought care/support related to the symptoms, as consistent with other studies (Clare, 2002; Garwick et al., 1994; Robinson, Clare, & Evans, 2005). During a qualitative study (Garwick et al., 1994) of family perceptions of AD, a theme emerged that exemplified that part of the sense making process in which family members first recognize "something is wrong". As identified in Garwick et al. (1994), and the current study, most family members recognized that something was wrong long before a diagnosis of AD is received. It is at this time, when the process of making sense of the experience begins. Several themes that emerged from Robinson, Clare, & Evan's study were descriptive of the process of gradually

making sense of AD. For some couples in this study and other studies, the time leading up to the diagnosis was the most frustrating and taxing on their relationship (Carpenter et al., 2008; Robinson, Clare, & Evans, 2005). Having an explanation for the symptoms seemed to help couples make sense of their experience and come to terms with the disease. Couples reported that the period prior to the diagnosis was often filled with frustration, arguments, and confusion. As discussed in the literature review, a recent study was conducted on 90 individuals and their partners, prior to and following the diagnosis of Mild Cognitive Impairment (MCI) or AD to examine short-term changes in depression and anxiety after receiving a dementia diagnosis (Carpenter, et al., 2008). Their findings revealed that little change was seen in depressive symptoms, yet symptoms of anxiety seemed to decrease after diagnostic feedback. More specifically, individuals who started their study with high levels of anxiety often experienced significant relief following a formal evaluation and diagnosis. As seen in this study, the formal diagnosis of MCI or AD, offered couples an explanation for symptoms that were creating frustration and confusion.

The idea that sense making is a process is not new to research grounded in a social constructionist framework. However, this study reinforced the social constructionist view that meaning is constructed daily by our interactions and experiences. For example, the couples in this study began making sense of their experience when symptoms were first recognized, further made sense of it during the interview as they shared their experiences, and likely will continue to make sense of it as each day evolves. Clare (2002) interviewed individuals with AD and their spouses separately to understand how individuals and their partners cope and adjust to the onset of AD. Clare suggested that due to the progressive nature of the disorder, acceptance would seem likely to require continual renegotiation as circumstances changed. Similarly, the couples in this study often stated that they were doing ok now, but that they did not know how they would deal with things as the disease progressed. Most of the couples in this study acknowledged that they did not know what their responses would be later on in the disease process but expected that they would be different if asked the same questions again. This also implies that how a couple deals with the diagnosis today, may be very different that how they deal with the diagnosis tomorrow.

### ***Meaning is Derived from the Interplay of Biopsychosocial-Spiritual Experiences***

Each couple's process of sense making regarding the diagnosis of AD was informed by the interplay of their physical experience (e.g., symptoms, duration, diagnosis process), their

psychological experience (e.g., thoughts, emotions, coping skills), their social experiences (e.g., impact on relationships, social support, resources), and their spiritual experience (e.g., religious/spiritual beliefs, values, life perspectives). Although themes were identified according to domain for clarity and organization purposes, couples made sense of and experienced AD based on the interaction of biological, psychological, social, and spiritual factors. The themes were organized according to domain to display to readers the various components of each domain, however; in actuality there is an interconnection among all domains, thus creating a systemic view of couples' experience. It must be noted that a systems view emphasizes the 'whole being greater than the sum of its parts'. Individually the themes of each domain do not mean or say as much if they are not in the context of the entire biopsychosocial-spiritual framework. This relates back to the idea of illness being context bound, as described in Chapter Two.

The findings of this study reinforced the view that illness is influenced by an individual's biology, psychology, and his/her social environment as discussed by Petersen and Benishek (2001). Some researchers have used the biopsychosocial model to review and conceptualize illness experiences in a systemic manner, thus highlighting the importance of a systemic framework, such as the one used in this study (Kunkel et al., 2000; Ownsworth et al., 2006) When exploring the patient experience of making sense of MCI, researchers found that the following factors were influential in shaping how individuals made sense of a diagnosis of MCI: expectations of normal aging, prior personal experience with dementia, and concurrent health status (Hagerty Lingler et al., 2006). This finding illustrated that even when a biopsychosocial framework is not guiding the study, biological, psychological and social factors emerge as important elements of making sense of a diagnosis such as MCI or AD.

A few studies have explored the psychological and social experiences of receiving an AD diagnosis from the patient perspective and the couple perspective (Carpenter et al., 2008; Robinson et al., 2005). A phenomenological study was conducted on the biopsychosocial impact of end-stage renal disease based on the experience of dialysis patients and the partners (White and Grenyer, 1999). Although, this study was conducted on a different disease, its emphasis on the biopsychosocial impact resulted in a similar process and similar kinds of results as this study on AD. The main differences were that the study by White and Grenyer was on renal disease and interviewed patients and their partners separately over the phone. The results of their study

illustrated the complex interaction between therapy, illness perceptions, relationship factors, social role disruptions, and emotional states. The present study also demonstrated an interaction between similar aspects such as treatment, diagnosis experiences, emotional reactions to the diagnosis, and various relationship factors.

### ***Meaning is Constructed One Day at a Time***

Couples in this study and in other studies tend to describe the process of making sense of and coping with AD by taking it ‘one day at a time’ (Garwick et al., 1994; Robinson et al., 2005). All but one couple in this study expressed their approach to coping with the disease as something that occurs day by day. Garwick et al., (1994) highlighted the unpredictable, uncertain life that comes with living with AD. Since there is so much uncertainty with AD, it makes sense that couples try to focus on getting through one day at a time, rather than try to deal with it all at once. If it is the case that couples are coping with the disease one day at a time, then it is likely that meaning is also being created one day at a time. Similar to this study, researchers explored how couples made sense of dementia and adjusted to loss, focusing on their psychological reactions (Robinson et al., 2005). These researchers identified a theme ‘take it as it comes’, which was almost identical to one of the parallel themes identified in this study, *day by day*. In both studies, couples expressed a desire to continue on with their lives as they always had and take things one day at a time. Couples were able to make sense of the experience based on that day, but were quick to acknowledge that each day is a new day. Therefore, the meaning couples attach to their experience is constructed one day at a time, leaving room for growth, change, and adjustment as each new experience arises.

### ***Worries about the Future Emerge During the Process of Meaning Construction***

Couples suggested a desire to make sense of what the disease is going to mean for their lives and their relationship as it progresses. Recent studies of caregivers and couples’ experiences with AD, have resulted in themes related to coping and social support similar to this study (Daniels et al., 2007, Garwick et al., 1994; Robinson et al., 2005; Sanders et al., 2007). A study on patient experiences of early AD has also revealed an emphasis on the uncertainty of the future of the disease (Pearce, et al., 2002). In a previous case study (Daniels et al., 2007) of the marital relationship and AD, worries about the future emerged as a central theme of the couples’

experience. The couple in the case study, similar to the couples in this study, started worrying about the future and thinking about possible changes that might occur due to the progression of the AD. Robinson, Clare, and Evans (2005) conducted a study exploring the psychological reactions to a diagnosis of dementia for nine married couples in which one spouse had received a diagnosis of dementia during the previous two years. These researchers used an interpretive phenomenological analysis, in which ten main themes emerged. Of the ten themes that emerged in their study, six of them were similar to themes that emerged in the present study. Similar to the Robinson, Clare, and Evans (2005) study, this study resulted in a theme specific to the experience of symptoms. Couples in the Robinson, Clare and Evans study reported changes such as, differences in memory functioning, mood, and temperament. Differences in memory functioning were similarly reported in both studies, however; mood and temperament changes of the spouse with AD were not reported in this study. This could be explained by the different window of diagnosis prior to interviewing patients. Other researchers also found that families in general expressed uncertainty as they processed the early stages of AD (Garwick et al., 1994).

This study resulted in some differences compared to the study by Robinson, Clare, and Evans (2005). For example, a theme identified from the study by Robinson, Clare, and Evans was descriptive of couples' dissatisfaction with services and information they received from their healthcare professionals. This study had a theme of couples questioning the doctors, however; of the four couples, none of them expressed dissatisfaction with the care they received.

### ***A Couple's Social Context is Important to Adjusting and Coping with an AD Diagnosis***

Although AD is a biological disease, Lyman (1989) explained that it is also a social disease which is spread descriptively as much as it is contracted (i.e., AD as a social construct has an infectious aspect that AD as a biological disease lacks). This implies that AD carries a social stigma which is transmitted socially and culturally through language and interactions. All but one couple in this study expressed some aspects of relationship strain, a finding also shared by Sorensen, Waldorff, and Waldemar (2008). These researchers explored how individuals with mild AD made sense of and coped with changes in their life and social relations. The participants in their study expressed that their spouses got frustrated or angry with them when they did not remember things. Participants with AD in this study and their spouses both acknowledged this frustration. In this study the spouses without AD were more aware of their own frustration and temper with their spouse's symptoms, than the person with AD.

In this study, the social aspects of couples' experiences seemed important to the sense making process and adjustment to the disease. Individuals in this study with AD put an emphasis on being able to continue functioning normally as much as they could and maintain involvement in their usual social activities. Pearce, Clare, and Pistrang (2002), examined the coping processes of 20 men diagnosed with early-stage Alzheimer's disease. When Pearce et al., (2002) explored how men with early-stage AD coped with their diagnosis, they found that it was important for men to maintain their sense of self as much as they could and view their disease as having limited impact on everyday functioning. Similarly, it also seemed important to the individuals with AD in this study, to view themselves as still active in their lives and in their social activities.

### ***Unique Contributions***

This particular study added to the current literature and knowledge of couples' experiences of receiving an AD diagnosis in distinct ways. First, the short timeframe in which the couples were interviewed following the diagnosis of AD, allowed us to gain a true perspective of what couples experience shortly following the diagnosis. Most studies that have explored meaning attached to an AD diagnosis have done so a year or two following the diagnosis. This time frame was also intended to capture couples currently in the process of making sense of the diagnosis. The benefit of this was not only to strengthen the ability to learn how couples experience a diagnosis, but to also provide a context during the interview in which meaning making between the couple may take place.

Another unique contribution was interviewing patients from a biopsychosocial-spiritual framework. Although studies have been conducted on the psychosocial impact of a diagnosis of AD, no known studies have explored couples' experiences from a systemic biopsychosocial-spiritual perspective. This enabled us to gain a more holistic understanding of couples' experiences, and allowed couples the opportunity to share their thoughts on many different aspects of the experience rather than to just focus on one.

### **Strengths and Limitations**

Along with this qualitative study came its own set of strengths and limitations. Strengths of this study were attributed to the focus of the study, the underlying framework of the study, and methodological choices. Limitations related to the sample techniques, the nature of qualitative research, and modes of data collection.



### *Strengths of Study*

A main strength of this study in general was the focus of the research. The focus on couples' experiences within two months of a diagnosis of AD captured in real time how couples were attempting to make sense of their experience. It allowed an opportunity for understanding how couples cope, make sense of, and adjust shortly following the diagnosis of AD. It also offered couples an opportunity to make sense of their experience with each other, as they shared their thoughts, emotions, and beliefs about the process.

One of the main strengths of this study was having a marriage and family therapist and a primary care physician as the two interpreters of the study. Having an expert in psychosocial issues work with an expert of medical/biological problems was a way to stay consistent with the biopsychosocial paradigm and offer different perspectives when analyzing the data. The involvement of two interpreters with different knowledge bases and different mindsets led to frequent questioning and discussions. Frequent questioning and discussions between the investigators allowed them plenty of time to check the meaning of the statement to make sure that the participant's voices emerged.

The social constructionist framework offered other strengths to the study. According to this framework, I viewed the perspectives of the individual with AD, his or her spouse, and the couple relationship equally as valuable to the construction of meaning. The process of gathering information from both spouses, served to empower the couple, but also served to gather a more holistic perspective of the AD patient, their spouse, and their relationship. An additional strength of the social constructionist approach to research was that it allowed us to view illness as context-bound. The ability to view illness as embedded in a larger context enhanced my ability to construct questions inquisitive about various meanings surrounding the illness. Finally, one of the greatest strengths of the social constructionist perspective with this study was the flexible and realistic nature of the approach. A social constructionist approach was naturally flexible, due to the emphasis on multiple perspectives and unique meanings that emerged from language and interaction. It was an approach that could be applied easily to various subsystems within the family.

The biopsychosocial-spiritual perspective was a significant strength of this study. Inquiring about biological, psychological, social, and spiritual domains of experience allowed the investigator to gain a broader understanding of each couple's experience. Significant components

of couples' experiences emerged as a result of the systemic questioning. The meaning constructed by couples around the AD diagnosis process was often a result of the interaction among the four domains. The biopsychosocial-spiritual experiences of each couple provided an overall context for their responses and construction of meaning. For example, participants' psychological experiences took on a different meaning when viewed in the systemic context of their entire experience, than they would if they were viewed separately.

### ***Limitations of Study***

Limitations of the study include the subjectivity of qualitative research, the small and narrow sample, and a one time interview with the couple. Although qualitative research allowed for rich collection of data, one of the limitations is the subjectivity that comes along with the investigators being the primary instruments of data collection. It is likely that a different investigator would have yielded different results due to their style of interviewing and interpretation. An additional limitation was the inability to generalize the results to other couples going through the same experience. A more generalizable sample would be able to offer stronger implications for researchers and various healthcare providers. Furthermore, the sample was small and thus had little diversity. Limitations were linked to a smaller sample than the investigator had originally anticipated. A larger sample with more diversity among race, social class, occupation, length of marriage, and number of children, might have produced different results. Last, limitations came with only having a one-time qualitative interview with the couple. A quantitative component in addition to the interview would have added another source of data collection, therefore, strengthening the results. Also, only interviewing the couple together could have prevented each individual from sharing important aspects of their experience that they did not feel comfortable expressing in front of their spouse. Furthermore, more interviews with the couples would have expanded the amount of information by capturing different points in the meaning construction process.

### **Future Implications**

Although this study was exploratory in nature, findings emerged that could inform clinicians and researchers of important issues to be aware of when considering couples in which one spouse has been diagnosed with AD. Clinical and research implications were offered in

hopes of expanding and enhancing both clinicians' and researchers' understanding of what couples experience when one spouse is diagnosed with AD.

### *Clinical Implications*

The findings of this study have implications for clinicians working with individuals, couples, and families recently impacted by an AD diagnosis. First, both a social constructionist perspective and a biopsychosocial-spiritual perspective could be extremely useful in healthcare settings. One of the greatest recommendations for clinicians that emerged from this study was that understanding how couples make sense of and experience an AD diagnosis involves a systemic assessment. If a clinician does not inquire about the couples' experience from a biopsychosocial-spiritual perspective a significant aspect of their experience could be missed. For physicians, nurses, family therapists, social workers, or other healthcare providers working in the medical setting, a social constructionist perspective may offer a helpful way of communicating and interacting with patients and their family members about AD. For example, Brown (1995) described diagnosis as being a central component in the work of all medical professionals, which is often the primary source of determining treatment. He also described the diagnosis process as central to subsequent constructions of illness. When a couple is diagnosed with AD, they are confronted, not only with a disease, but also an illness that unexpectedly enters their relationship. According to Brown (1995), although it is strongly affected by social forces, disease is a biomedical phenomenon, whereas, illness is a more subjective, socially constructed phenomenon. Providing healthcare professionals with an understanding of the social construction of illness might enhance their ability to effectively and empathically communicate with AD patients and their spouses.

In his book, "The Wounded Storyteller", Arthur Frank (1995) spoke in-depth about the need for ill people to share their illness stories. He described that illness stories serve two purposes for those that are diagnosed with a serious illness. The first is that stories repair the damage that the illness has done to the person's sense of where they have been and where they are headed in life. For example, stories could be a way for a couple to draw a map of where their relationship is headed and find new destinations that are not restricted by the AD. The second purpose of illness stories is that of needing to tell the actual story of the illness, whether to health care providers, employers, family members, or friends. Clinicians' inquiry of couple's

experiences would be a realistic, practicable, and valuable way of exploring how couples share and construct their illness stories. Results from this study suggest that a couples' social support and spirituality could influence their experience significantly. It is recommended that clinicians take time to learn the type of support couples have available and encourage support services if applicable.

This study provided merely another step towards understanding how couples experience and make sense of a diagnosis of AD. Many implications for future research emerged throughout this study. Following her study, Wright (1991) suggested that healthcare professionals take on the task of supporting both the afflicted spouse with AD and the caregiver. However, one way healthcare professionals can demonstrate this support for both spouses, is by including both of them in research. This study also highlighted the importance of hearing both spouses perspectives and valuing their input. Yet, there is a reason that this has not been done very often. After studying both spouses together, Wright noted that it was a difficult task to gain information about the couple relationship from both spouses. Wright stated that during the interview process, responses of participants' with AD were often tangential and required a significant amount of patience from the interviewers. However, she also observed that the AD participants' answers toward many of the questions about their marital relationship showed more awareness than she had anticipated. The primary investigator of this study strongly agrees with Wright's perspective and encourages all healthcare providers to include and respect the input of both individuals in the relationship when one is diagnosed with AD.

### ***Research Implications and Future Directions***

Although it appears to be a difficult task, more research is needed that includes the couple as the unit of analysis, in order to gain an adequate understanding of how couples construct meaning surrounding an AD diagnosis. A larger sample size is critical to fully understanding the biopsychosocial-spiritual experience of couples dealing with an AD diagnosis. More research is needed on both couples' perspectives of the diagnosis experience as well as, the individual's perspectives. It would be interesting to see if there are differences in the reported experience when sharing responses individually, in comparison to sharing responses in front of your spouse.

The spiritual component of this study raised interesting questions for future research to explore. Do couples with a strong faith foundation cope and adjust better to a diagnosis of AD?

Does the perception of couple's experiences correlate with their level of belief and trust in God? What aspects of spirituality assist in the construction of meaning of an AD diagnosis? All of the previous questions could expand our understanding of the connection between spirituality and illness experiences.

More research is needed using a biopsychosocial-spiritual approach to understanding the experience of an AD diagnosis. Very little research is focused on understanding the experience of those coping with AD from a systemic perspective. A systemic perspective will enhance the overall understanding of couples' needs during the process of being diagnosed with AD. It will allow clinicians and researchers to target how different factors work together to influence how couples adjust to a diagnosis of AD.

## **Conclusion**

In conclusion, this dissertation provided an in-depth description of an explorative study about how couples experience and make sense of AD within two months of a diagnosis. The study was guided by the theoretical framework of social constructionism and the biopsychosocial-spiritual perspective. These frameworks allowed the investigators to explore the meaning of a diagnosis of AD for married couples from a systemic perspective. The study resulted in rich descriptions of four couples' experiences of an AD diagnosis among biological, psychological, social, and spiritual domains. Similarities and differences among the four couples emerged as they shared their experiences. The results of the study highlighted the importance of exploring all aspects of couple's experiences in order to understand how to best work with them and provide care for them. This study revealed that the diagnosis of AD affects many different aspects of a marriage, just as many different aspects of a couple's life affect how they experience, adjust, and cope with an AD diagnosis. This phenomenological study was the first to explore how couples experience and make sense of a diagnosis of AD, within months following the diagnosis, from a biopsychosocial-spiritual perspective.

## References

- Alzheimer's Disease Education & Referral Center. (2005). *Progress report on Alzheimer's disease 2004-2005*. National Institute for Aging.
- Alzheimer's Disease and Related Disorders Association, Inc. (2008). *Facts and Figures* (2008). <http://www.alz.org>
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (text revision). Washington, DC: American Psychiatric Association.
- Anderson, H. (2002). *Becoming a postmodern collaborative therapist: A clinical and theoretical journey, Part II*.
- Anderson, H. (1996). A reflection on client-professional collaboration. *Families, Systems, and Health, 14*(2), 193-206.
- Berger, P., & Luckman, T. (1966). *The social construction of reality*. New York: Doubleday and Co.
- Blieszner, R. & Shifflett, P. A. (1990). The effects of Alzheimer's disease on close relationships between patients and caregivers. *Family Relations, 39*, 57-62.
- Brown, P. (1995). Naming and framing: The social construction of diagnosis and illness. *Journal of Health and Social Behavior, 35*, 34-52.
- Burns, A., Byrne, E. J., Maurer, K., & Lancet (2002). *Alzheimer's disease*. 360(9327), 163-168.
- Butcher, H. K., Holkup, P. A., & Buckwalter, K. C. (2001). The experience of caring for a family member with Alzheimer's disease. *Western Journal of Nursing Research, 23*, 33-55.
- Carpenter, B. D., Chengjie, X., Porensky, E. K., Lee, M. M., Brown, P. J., Coats, M., Johnson, D., & Morris, J. C. (2008). Reaction to a dementia diagnosis in individuals with Alzheimer's disease and mild cognitive impairment. *Journal of American Geriatrics Society, 56*, 405-412.
- Centers for Disease Control and Prevention. (2008). *Chronic Disease Prevention and Health Promotion*. Department of Health and Human Services. <http://www.cdc.gov/nccdphp/overview.htm>
- Clare, L. (2002). We'll fight it as long as we can: Coping with the onset of Alzheimer's disease. *Aging and Mental Health, 6*(2), 139-148.

- Clare, L. (2004). The construction of awareness in early-stage Alzheimer's disease: A review of concepts and models. *British Journal of Clinical Psychology, 43*, 155-175.
- Cotrell, V., & Schulz, R. (1993). The perspective of the patient with Alzheimer's disease: A neglected dimension of dementia research. *The Gerontologist, 33*, 205-211.
- Creswell, J. W. (1994). *Research Design: Qualitative & Quantitative Approaches*. Thousand Oaks, CA: Sage Publications.
- Daniels, K. J., Lamson, A. L., & Hodgson, J. (2007). An exploration of the marital relationship and Alzheimer's Disease: One couple's story. *Families, Systems, and Health, 25*(2), 162-177.
- Denzin, N. K., & Lincoln, Y. S. (2000). *Handbook of Qualitative Research* (2<sup>nd</sup> Ed.). Thousand Oaks, CA: Sage Publications.
- Engle, (1977). The need for a new medical model: a challenge for biomedicine. *Science, 196*(4286), 129-136.
- Engle, (1980). The clinical application of the biopsychosocial model. *American Journal of Psychiatry, 137*, 535-544.
- Foxall, M. J., Ekberg, J. Y., Griffith., N., & Davis, B. A. (1985). Adjustment patterns of chronically ill middle aged persons and spouses. *Western Journal of Nursing Research, 7*, 425-444.
- Frank, A. W. (1995). *The wounded storyteller*. The University of Chicago Press.
- Freedman, J. & Combs, G. (1996). *Narrative Therapy: The social construction of preferred realities*. W. W. Norton & Company, NY.
- Frishman, R. G. (1997). The race for Alzheimer's treatments. *Harvard Health Letter, 22*, 1-3.
- Gallagher-Thompson, D., Dal Canto, P. G., Jacob, T., & Thompson, L. W. (2001) A comparison of marital interaction patterns between couples in which the husband does or does not have Alzheimer's disease. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 56*, S140-S150.
- Garand, L., Dew, M. A., Hagerty Lingler, J., DeKosky, S. T., & Reynolds III, C. F. (2007). Marital quality in the context of mild cognitive impairment. *Western Journal of Nursing Research, 29*(8), 976-992.
- Garwick, A. W., Detzner, D., & Boss, P. (1994). Family perceptions of living with Alzheimer's Disease. *Family Process, 33*, 327-340.

- Gergen, K. J. (1994). *Realities and relationships: Soundings in social construction*. Cambridge, MA: Harvard University Press.
- Giorgi, (1985). *Phenomenology and psychological research*. Duquesne University Press.
- Gruetzner, H. (1992). *Alzheimer's: A caregiver's guide and sourcebook* (Rev. ed.). Waco, TX: John Wiley & Sons.
- Gubrium, J. F. (1986). *Oldtimers and Alzheimer's: The descriptive organization of senility*. Greenwich, CT: JAI Press.
- Gubrium, J. F. (1988). Family responsibility and care giving in the qualitative analysis of the Alzheimer's disease experience. *Journal of Marriage and Family Therapy*, 50, 197-207.
- Gubrium, J. F., & Holstein, J. A. (2003). Analyzing interpretive practice. In N. K. Denzin & Y. S. Lincoln (Eds.), *Strategies of qualitative inquiry*. Thousand Oaks, CA: Sage Publications, Inc.
- Gwyther, L. P. (1985). *Care of Alzheimer's patients: A manual for nursing home staff* (pp. 25-27). American Health Care Association and ADRDA, Inc.
- Habermann, B. (2000). Spousal perspective of Parkinson's disease in middle life. *Journal of Advanced Nursing*, 31(6), 1409-1415.
- Haftstrom, J. L. & Schram, V. R. (1984). Chronic illness in couples: Selected characteristics, including wife's satisfaction with and perception of marital relationships. *Family Relations*, 33, 195-203.
- Hagerty Lingler, J., Nightingale, M. C., Erlen, J. A., Kane, A. L., Reynolds III, C. F., Schulz, R., & DeKosky, S. T. (2006). Making sense of mild cognitive impairment: A qualitative exploration of the patient's experience. *The Gerontologist*, 46(6), 791-800.
- Heijmans, M., DeRidder, D., & Bensing, J. (1999). Dissimilarity in patients' and spouses' representations of chronic illness: Exploration of relations to patient adaptation. *Psychology and Health*, 14, 451-466.
- Kuhn, D. R. (1998). Caring for relatives with early stage Alzheimer's disease: An exploratory study. *American Journal of Alzheimer's Disease*, 189-196.
- Kunkel, E. J. S., Bakker, J. R., Myers, R. E., Oyesanmi, O., & Gomella, L. G. (2000). Biopsychosocial aspects of prostate cancer. *Psychosomatics*, 41(2), 85-94.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic Inquiry*. Newbury Park, CA: Sage Publications.



- Lyman, K. A. (1989). Bringing the social back in: A critique of the biomedicalization of dementia. *The Gerontologist*, 29 (5), 597-606.
- Mace, N. L., & Rabins, P. V. (1999). *The 36-hour day: A family guide to caring for persons with Alzheimer disease, related dementing illness, and memory loss in later life* (3<sup>rd</sup> ed.). Baltimore: Johns Hopkins University Press.
- Merriam, S. B. (1998). *Qualitative research and case study applications in education* (Rev. ed.). San Francisco, CA: John Wiley & Sons, Inc.
- Miles, M. B. & Huberman, M. A. (1994). *Qualitative data analysis: An expanded sourcebook*. Thousand Oaks, CA: Sage Publications.
- Mittelman, M. S. (2002). Family caregiving for people with Alzheimer's disease: Results of the NYU spouse caregiver intervention study. *Mental Health and Mental Illness in Later Life*, 26, 104-106.
- Moustakas, C. (1994). *Phenomenological research methods*. Thousand Oaks, CA: Sage Publications.
- Moustakas, C., & Douglass, B. G. (1985). Heuristic inquiry: The internal search to know. *Journal of Humanistic Psychology*, 25(3), 39-55.
- National Institute on Aging. (2007). *Progress report on Alzheimer's disease (2004-2005)*. Retrieved 2007, from <http://www.alzresearch.org/disease.cfm>
- Owensworth, T., Clare, L., & Morris, R. (2006). An integrated biopsychosocial approach to understanding awareness deficits in Alzheimer's disease and brain injury. *Neuropsychological Rehabilitation*, 16(4), 415-438.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods*, 3<sup>rd</sup> ed. Thousand Oaks, CA: Sage.
- Patterson, J. M., & Garwick, A. W. (1994). Special Section: Chronic Illness and the Family. Levels of meaning in family stress theory. *Family Process*, 33, 287-304.
- Pearce, A., Clare, L., & Pistrang, N. (2002). Managing sense of self: Coping in the early stages of Alzheimer's disease. *Dementia*, 1(2), 173-192.
- Petersen, S., & Benishek, L. A. (2001). Social construction of illness: Addressing the impact of cancer on women in therapy. *Minding the Body: Psychotherapy in Cases of Chronic and Life-Threatening Illness*, 23(1), 75-100.
- Polkinghorne, D. E. (1989). Reporting qualitative research. *Methods*, 3, 63-85.

- Pratt, R. & Wilkinson, H. (2003). A psychosocial model of understanding the experience of receiving a diagnosis of dementia. *Dementia, 2*(2), 181-199.
- Robinson, L., Clare, L., & Evans, K. (2005). Making sense of dementia and adjusting to loss: Psychological reactions to a diagnosis of dementia in couples. *Aging and Mental Health, 9*(4), 337-347.
- Rolland, J. S. (1994). In sickness and in health: The impact of illness on couples' relationships. *Journal of Marital and Family Therapy, 20*, 327-347.
- Sanders, S., Ott, C. H., Kelber, S. T., & Noonan, P. (2007). The experience of high levels of grief in caregivers of persons with Alzheimer's disease and related dementia. *Death Studies, 32*, 495-523.
- Seaburn, D., Gawinski, B., Harp, J., McDaniel, S., Waxman, D., & Shields, C. (1993). Family systems therapy in a primary care medical setting: The Rochester experience. *Journal of Marital and Family Therapy, 19*(2), 177-190.
- Selkoe, D. J. (1997). Alzheimer's disease: genotypes, phenotype, and treatments. *Neuroscience, 275*(5300).
- Smith, A. P. & Beattie, B. L. (2001). Disclosing a diagnosis of Alzheimer's disease: Patient and family experiences. *The Canadian Journal of Neurological Sciences, 28*, 67-71.
- Sorensen, L., Waldorff, F., & Waldemar, G. (2008). Coping with mild Alzheimer's Disease. *Dementia, 7*(3), 287-299.
- White, M., & Epston, D. (1990). *Narrative means to therapeutic ends*. W. W. Norton & Company, NY & London.
- White, Y., & Grenyer, B.F. (1999). The biopsychosocial impact of end-stage renal disease: the experience of dialysis patients and their partners. *Journal of Advanced Nursing, 30*(6), 1312-1320.
- Wright, L. K. (1991). The impact of Alzheimer's disease on the marital relationship. *The Gerontologist, 31*(2), 224-237.

## **Appendix A - Recruitment Flyer**

Recruitment for Study on Alzheimer's Disease:

### **Couples' Construction of Meaning of an Alzheimer's Disease Diagnosis:**

#### **A Systemic Approach to Meaning Making**

*Primary Investigator: Katherine J. Daniels, 559-7545*

#### General Description of Study

Alzheimer's disease (AD) is a chronic illness that has the capacity to impact several domains of a person's life. This study is part of a dissertation that is being conducted to fulfill the requirements for Katherine Daniels' PhD in Marriage and Family Therapy at Kansas State University. The focus of this study will be to explore four particular domains of meaning that couples construct surrounding an AD diagnosis. In this qualitative study, a social constructionist framework will be used to explore the biological, psychological, social, and spiritual factors which inform and possibly influence how couples experience an AD diagnosis. The researcher will conduct one face-to-face interview with each participating couple, with both spouses at the same time, no more than two months following a formal diagnosis of AD. This particular time frame is intended to capture the raw experience couples go through when receiving an AD diagnosis. The interview will take between 60-90 minutes and will consist of open-ended questions about the couple's experience of the diagnosis process.

#### Sample

The sample in this particular study will consist of seven to ten couples. Participants will be recruited from several sites affiliated with Nebraska Medical Center. This study has gained approval from the Institutional Review Boards (IRB) at both Nebraska Medical Center and Kansas State University. Participants may either call the primary researcher or give permission for the researcher to contact them.

To be eligible for this study, participants must meet the following criteria:

- 6) One of the spouses has received a formal AD diagnosis.
- 7) Both spouses speak English.
- 8) The person with AD has been married for 10 years or more, and
- 9) The couple resides together, either in a residential home, or long-term care facility.

Participants will be required to read and sign the informed consent, explaining the potential risks and protections involved in the study. If the spouse with Alzheimer's disease is not able to provide their own consent, his/her spouse must be able to provide consent for them. Each interview will be audio-taped and video-taped (for a back up method), then transcribed. Consent will be obtained prior to the recording of any data, whether written by the researcher or audio-taped. Audio-tapes of interviews will be kept in a locked file cabinet, identified by numerical codes. The data will be collected by conducting one face-to-face interview with each participating couple. Following the interviews participants will be given relevant resources for further information and support.

Please contact me at 402-559-7545 or [kjdaniels@unmc.edu](mailto:kjdaniels@unmc.edu) if you are interested in participating or learning more about the study.

Katie Daniels, MS, LMFT

## **Appendix B - Informed Consent**



### **ADULT CONSENT FORM**

#### **Title of this Research Study**

**COUPLES' CONSTRUCTION OF MEANING OF AN ALZHEIMER'S DISEASE  
DIAGNOSIS: A SYSTEMIC APPROACH**

#### **Invitation**

You are invited to take part in this research study. The information in this form is meant to help you decide whether or not to take part. If you have any questions, please ask.

#### **Why are you being asked to be in this research study?**

You are being asked to participate in this study because you are an individual who has either been diagnosed or whose spouse has been diagnosed with Alzheimer's disease within the past two months. You and your spouse were identified as eligible participants because you have been married for at least 10 years and currently live together in a private residence.

#### **What is the reason for doing this research study?**

The purpose of this research study is to gain an understanding of how the diagnosis of Alzheimer's disease affects the life and experience of married couples from a systemic perspective. The study will explore how the diagnosis of AD impacts couple relationships, physically, psychologically, socially, and spiritually.

#### **What will be done during this research study?**

The study will consist of one interview with both spouses present. The interview will be conducted in one sitting in a place of your choice. Katherine Daniels, the principle researcher, will interview you as a couple (together). She will ask you questions about how you feel your lives have been affected by the diagnosis. The questions will focus on how the diagnosis has affected you -- as a couple -- physically, psychologically, socially, and spiritually. The researcher will be studying how couples portray their experience of receiving an Alzheimer's disease

diagnosis. Prior to conducting the interviews, the researcher will obtain the following information from the medical records of the participants: demographic information, Mini-Mental Status Exam (MMSE) scores, description, duration, and severity of symptoms. The researcher will be interested in both spouses' perceptions of how the disease has impacted physical, psychological, social, and spiritual aspects of their relationship. It should pose no inconvenience to you and should last no more 90 minutes. To help us understand and to use the information you provide, we seek your permission here to videotape and audiotape this interview session. All video and audiotapes will be kept in a locked file box, and will be erased following completion of the study and write-up of the study.

**What are the possible risks of being in this research study?**

Possible discomfort with the interview process or specific questions may be associated with this study. We will remain sensitive to the comfort level of each couple, particularly due to the personal aspects questions regarding marital relationship and the recent diagnosis process. For example, questions will be asked about areas of marital relations affected by the intrusion of AD, including communication and intimacy, role-relationships, marital satisfaction, spirituality, family relationships, or points of marital conflict or concern mentioned by the couple.

**What are the possible benefits to you?**

You may benefit emotionally from the opportunity to share your experience together as a couple. However, you may not get any benefit from being in this research study.

**What are the possible benefits to other people?**

The potential benefits of the study to others lie in the opportunity to enhance the amount and quality of information on couples and AD. Other healthcare providers may learn more effective ways of supporting and caring for those experiencing AD.

**What are the alternatives to being in this research study?**

Instead of being in this research study, you can choose not to participate. The researcher will still provide you with a packet of relevant information and community resources.

**What will participating in this research study cost you?**

There is no cost to you to be in this research study.

**Will you be paid for being in this research study?**

You will not be paid to be in this research study.

**What should you do if you have a problem during this research study?**

Your welfare is the major concern of every member of the research team. If you have a problem as a direct result of being in this study, you should immediately contact one of the people listed at the end of this consent form.

### **How will information about you be protected?**

You have rights regarding the privacy of your medical information collected before and during this research. This medical information, “protected health information” (PHI), includes demographic information (like your address and birth date), the results of physical exams, documentation of symptoms of the disease and other diagnostic and medical procedures occurring throughout the diagnostic process. You have the right to limit the use and sharing of your PHI, and you have the right to see your medical records and know who else is seeing them. Your PHI will be used only for the purpose(s) described in the section “What is the reason for doing this research study?”

By signing the consent form, you are allowing the research team to have access to your PHI. The research team includes the investigators listed on this consent form and other personnel involved in this specific study at UNMC and the Nebraska Medical Center.

You may cancel this authorization to use and share your PHI at any time by contacting the principal investigator in writing. If you cancel this authorization, you may no longer participate in this research. If you cancel this authorization, use or sharing of future PHI will be stopped. The PHI which has already been collected may still be used.

Reasonable steps will be taken to protect your privacy and the confidentiality of your study data. All information you provide to us will be stored in a secure environment. The only people who will have access to the information collected in this study are Ms. Katherine Daniels, Dr. Rick Scheidt at Kansas State University, and the IRB. When the study is done, we would eventually like to share a summary of the information with other professionals. However, no personally-identifying information will be used when we do this. If other coders are necessary to analyze or offer opinions about the data, they will be qualified trained professionals and approved by the University of Nebraska Medical Center Institutional Review Board and the Kansas State University Institutional Review Board.

The only persons who will have access to your research records are the study personnel, the Institutional Review Board (IRB), and any other person or agency required by law. The information from this study may be published in scientific journals or presented at scientific meetings but your identity will be kept strictly confidential.

### **What are your rights as a research subject?**

You have rights as a research subject. These rights have been explained in this consent form and in The Rights of Research Subjects that you have been given. If you have any questions concerning your rights or complaints about the research, talk to the investigator or contact the Institutional Review Board (IRB) by:

Telephone (402) 559-6463.

Email: [IRBORA@unmc.edu](mailto:IRBORA@unmc.edu)

Mail: UNMC Institutional Review Board, 987830 Nebraska Medical Center, Omaha, NE 68198-7830

**What will happen if you decide not to be in this research study or decide to stop participating once you start?**

You can decide not to be in this research study, or you can stop being in this research study (“withdraw”) at any time before, during, or after the research begins. Deciding not to be in this research study or deciding to withdraw will not affect your relationship with the investigator, or with the University of Nebraska Medical Center or The Nebraska Medical Center hospital.

You will not lose any benefits to which you are entitled.

If the research team gets any new information during this research study that may affect whether you would want to continue being in the study you will be informed promptly.

**Documentation of informed consent**

You are freely making a decision whether to be in this research study. Signing this form means that (1) you have read and understood this consent form, (2) you have had the consent form explained to you, (3) you have had your questions answered and (4) you have decided to be in the research study.

If you have any questions during the study, you should talk to one of the investigators listed below. You will be given a copy of this consent form to keep.

Printed Name of Subject: \_\_\_\_\_

Signature of Subject: \_\_\_\_\_ Date: \_\_\_\_\_

My signature certifies that all the elements of informed consent described on this consent form have been explained fully to the subject. In my judgment, the participant possesses the legal capacity to give informed consent to participate in this research and is voluntarily and knowingly giving informed consent to participate.

Signature of Person Obtaining Consent: \_\_\_\_\_ Date: \_\_\_\_\_

**Authorized Study Personnel**

Principal Investigator: Katherine Daniels, MS, LMFT (402) 559-7545

Secondary Investigator: Rick Scheidt, PhD (785) 532-1483

Participating Personnel: Timothy Malloy, MD (402) 559-7464

Data Management Personnel: Jennifer Buescher, MD, MSPH, (402) 552-2086

Administrative Personnel: Mary McAndrews, BA, (402) 559-9328



## Appendix C - Interview Guide

**Introductory questions:** The purpose of the introductory questions is to obtain some background and demographic information about the couples.

- How long have you been married?
- Is this your first marriage? When were you married previously?
- Do you have children? How many?
- What is your highest degree of education?
- What is (was) your occupation?
- How would you describe your relationship?

**Biological Questions:** The purpose of the biological questions is to explore the couples' understandings of the physical and medical aspects associated with the disease, as well as, their illness experience.

### **Overarching Biological Question:**

- *What have you as a couple experienced physically (signs, symptoms, behaviors, etc.) and medically (interaction with physicians, process of diagnosis, medications, etc.) throughout the diagnosis process?*
- When did you each first notice signs or symptoms of the disease? What were they? What did you attribute them to?
  - When did you first see a doctor about your symptoms?
  - When were you first given a diagnosis of Alzheimer's disease? How were you told?
  - How many medical opinions have you received?
  - What is your understanding of what the disease is, including the cause, symptoms, and course of the disease?
  - What has your experience with your medical providers been like?
  - Is there anything else that you view as an important component of your medical experience thus far?

**Psychological:** The purpose of the psychological questions is to explore the mental, emotional, and behavioral aspects that may have accompanied the disease, as well as, the couple's illness experience.

**Overarching Psychological Question:**

- *What have you experienced mentally and emotionally throughout the course of the disease?*
- What thoughts, questions or concerns have you had following the onset of AD symptoms?
  - How would you describe your attitude and mood throughout the diagnosis process? How would you describe your spouse's attitude or mood?
  - What emotions/feelings have you experienced throughout the diagnosis process?
  - What have been the most emotionally challenging aspects of your illness experience?
  - What or who do you feel has made this process harder or easier for you as a couple?
  - How have you as a couple been able to get through this experience?

**Social:** The purpose of the social questions is to explore the relationships that have impacted or been impacted by the disease and the couple's illness experience (e.g. spouses, family, friends, children, parents, healthcare providers, etc.)

**Overarching Social Question:**

- *How have your social lives and relationships been impacted throughout the diagnosis process?*
- How do you feel your marriage has been impacted throughout the course of the disease?
  - What social support have you received throughout this process?
  - How did your friends/family members react to your diagnosis?
  - Did any of your relationships change (positively or negatively) following the onset of your AD symptoms? Which ones? How did they change?
  - How have your family/friends showed you their care or concern during your illness experience?
  - What types of support services were offered to you by healthcare providers?
  - Were you pleased or disappointed with the amount and type of support you have received by friends, family, and healthcare providers? In what ways?

**Spiritual:** The purpose of the spiritual questions is to inquire about the beliefs and meanings that the couple has associated with the disease, including the role, if any, that religion or spirituality has had throughout the diagnosis process.

**Overarching Spiritual Question:**

➤ *What, religious, or spiritual experiences have accompanied the diagnosis process? How have these impacted your experience of receiving an AD diagnosis?*

6. What meaning has your experience with AD given to your life?
7. What are your spiritual/religious beliefs as a couple?
8. Have there been any changes to your spiritual, religious, or moral beliefs throughout the diagnosis experience?
9. As a couple, what type of plan or approach have you come up with for dealing with diagnosis process?

**Closing questions:** The purpose of the closing questions is to wrap-up the interview and give the couple space to add anything that they feel is important?

1. As a couple, what do you do together to cope with AD and everything that has come with it?
2. As a couple, have you developed any new strengths or resources following the onset of AD?
3. What is the single most important piece of advice you could offer to other couples going through the diagnosis process of AD?
4. Is there anything else that has been an important part of your experience that you would like to add?

## Appendix D - Case One: Complete Themes and Examples

Case 1, Husband has AD	
BIOLOGICAL	
Theme	Descriptive Examples
<b>Inability to Recall</b>	<p>H: But somebody that we had known for a long time, I'd call them Bob for 30 years and all of a sudden, I couldn't remember what their last name was and I would think and think and think and pretty soon, it would pop into my head or if it didn't, if you'd have taken and written ten names down on a piece of paper, I could have told you which one it was, so you know.</p> <p>H: It's my ability to bring them up when I need to and I still have some problems with that.</p> <p>H: The nerve cells have died and I've lost it and I haven't seen anything on the ability to recall something that is up there and that was my biggest initial problem.</p> <p>H: I went primarily because of this recall thing.</p> <p>H: 90 percent of my problem is I don't remember but I know I'm going to go somewhere and I forgot it and she'll tell me and then I might forget it again.</p> <p>H: I'll just...you knows, things will blank out on me, but it's still...the majority of the problems I'm experiencing right now is recall.</p>
<b>Experience of Symptoms Prior to Diagnosis</b>	<p>W: We went through some battle for him to take medicine. He hates taking medicine.</p> <p>H: I think it's been a couple of years.</p> <p>W: Well, we saw a doctor Bowman about five years ago or six years ago because I was worried about your memory and your depression.</p> <p>W: It's within six years ago. I mean, we went twice and they acted like it was kind of my hallucination that there was something wrong with him and they gave him a clear bill.</p> <p>W: And then gradually, I mean...I just accepted their word for it, so I just put it down to lack of attention until he was having anxiety and we went to Dr _____ on February 19<sup>th</sup>.</p> <p>W: And then when we came back to Omaha, is when I thought it started to show, so what it was related to could have been anything I guess.</p> <p>H: I didn't think I had Alzheimer's, but I didn't know because the problems got so bad and I read because of this recall thing primarily and I can go get some medication that will maybe help me with that.</p>
<b>Experience of Diagnosis Process</b>	<p>H: Just...“I think you're in the very early stages of Alzheimer's”.</p> <p>W: They asked us both a lot of questions and everything and he told him he thought this was it but then he sent him to a psychologist, Dr. _____.</p> <p>H: That's where I took all my tests. Numbers and words and all of that. He sent me there first and said he suspected it was and he sent me and I went through all the tests and then we went back to see _____ and after he got the test results back from Dr. _____, that's when he told us.</p> <p>H: That was a long haul. That thing was about what...three hours...the tests.</p>
<b>Current Experience of Symptoms</b>	<p>H: I still think that I'm in the pretty early stages because again,</p> <p>W: He's got to put on weight, so I've been shoving everything in his mouth and...cause he doesn't eat and I really, really...</p>

	<p>W: ... and now the only thing now is he's got to remember stuff.</p> <p>H: I don't know that I can blame Alzheimer's, but I've lost my appetite. I don't get hungry anymore.</p> <p>H: Right now, I can do anything that I ever did except remember what I had for breakfast. Then again, it's mostly recall</p> <p>H: The memory problems I'm having that beyond the recall...is very current short term</p> <p>H: I don't have any trouble following the plot and things like that and everything is very, very normal, but to get up the next morning and you ask me what did I watch on TV last night, I may or may not be able to tell you and then if you ask me what was that episode about, I can't...I can understand it when it's happening.</p> <p>H: but I mean as far as my ability to function, I can do everything I always did. Play golf...I can hit golf balls.</p>
<b>PSYCHOLOGICAL</b>	
<b>Theme</b>	<b>Descriptive Examples</b>
<b>Attribution of Symptoms</b>	<p>W: then it became pretty clear about a year ago that he was losing his memory. But I still thought it might be depression.</p> <p>W: And lack of attention.</p> <p>H: I attributed it to the aging process. You get old, you get forgetful.</p> <p>H: The fact that most of the time what I couldn't bring up was there. I said well that's not Alzheimer's. Alzheimer's, it goes away. You know it's gone. You're never going to remember it.</p> <p>H: So when I went in to see Dr._____, I had convinced myself that it probably wasn't Alzheimer's for that reason.</p> <p>W: Well one of the causes...we were kind of surprised is that they found out that he had had a traumatic head injury when he was 15 years old and we were both surprised to find out that number 1, it showed up in...there's a spot in the cat scan and he was unconscious.</p> <p>W: The thing that just throws me about Don and this has nothing to do with Alzheimer's. He closes his eyes during the ads and he just and I can never figure it out how he does that. He hasn't got a clue what the ad is about. You know and I'll say something, that's a cute ad. What ad? And he's laying on the couch and I'm sitting right there in his chair and he completely disappeared during the ad or something that he doesn't enjoy and it's like, come back, come back. And I really don't know what to blame it on...him or Alzheimer's.</p>
<b>Learning about AD</b>	<p>H: I mean I've read everything I can get my hands on about Alzheimer's and I think I've got, from a layman's standpoint, a pretty good understanding of it.</p> <p>H: I have read books. I've been on line. I've spent hours studying different articles and books on Alzheimer's so that I could understand what I was looking at</p> <p>H: I can't get it because it varies apparently so much and I won't lie, but everything that I can determine from start to finish is different than what you read. I've read five to ten years...I've read five to fifteen years. I've read ten to twenty years and....</p>

<p><b>Emotional Experience</b></p>	<p>H: Well, initially it hits you right between the eyes and you know, you don't like to hear bad news, but I'm convinced that I am in the very early stages. I think they're probably right.</p> <p>H: I took the test and everything and so most people, maybe it is a shock but with me, when he told me that it was, it was a shock.</p> <p>W: Depressed.</p> <p>W: Honestly, we have cried.</p> <p>W: ...there are times when ...I mean I knew this was going to happen...[crying] Yeah, it is tough.</p> <p>W: I'm scared.</p> <p>W: It's been up and down since February 21<sup>st</sup>.</p> <p>W: I know that ..it has made a difference ...a lot of times, when he knows that he can't remember something or anything, he gets frustrated and he gets crabby and there are times that I get frustrated with him and I get angry and that's the only thing...</p>
<p><b>Perception of Coping</b></p>	<p>W: Oh well, I'm a fighter.</p> <p>H: I suppose...I think I'm handling it really better than you do.</p> <p>H: The only thing that she has to cope with is me asking her questions about things that I should know, but you know, it's affected our lives emotionally, but it hasn't affected them.....</p> <p>W: I think we're two very strong people to begin with.</p> <p>H: I kind of convinced myself that they're probably right and that that's what it is, so I'm not in denial.</p>
<p><b>Uncertainty about the Future</b></p>	<p>W: Talking about it knowing it's....talking about it, knowing, not knowing when to do certain things like...will I know in advance before something happens that I can't drive anymore or ...</p> <p>H: Especially when they know that it's going to be long and progressive and it's just going to get worse and worse and worse and worse over a long, long period of time. Emotionally that's tough to deal with.</p> <p>W: I'm watching this friend of ours and I'm petrified of what's going to come and I know it's going to come.</p> <p>W: Anyway, this probably makes us look at the future more than what we might have looked at it differently and that's about it, I think.</p> <p>H: But when somebody gets bad news like this...You know, I think we both know that if it ever gets that far, that it's going to be a lot tougher on her than it is on me, whatever.</p> <p>W: Looking ahead, thinking, you know...and our 50<sup>th</sup> anniversary and we want to go someplace and we want to...and I want to...I'm thinking...I'm waiting....going to be fine in a year from now...</p> <p>H: I'm not going to worry right now about when I get to the point that our good friend John is where he can't dress himself or he can't walk and things like that. I see no point in dwelling on that right now.</p> <p>H: we've got our insurance. We're both on Medicare. We've got our supplements and stuff like that, but beyond that, you know, I don't know what the financial burdens are going to be.</p> <p>H: Well, I'm not sure what I'm planning for. I'm not convinced that I'm going to have to spend the last several years of my life in a nursing home. Maybe I will but ...</p>
<p><b>Taking it Day by Day</b></p>	<p>H: I don't spend a lot of time thinking about it.</p> <p>H: Everything is fine right now. I mean, there's nothing I can't do.</p> <p>H: Right now, it's not causing a problem, you know, in our day-to-day living</p>

	<p>relationship or anything like that and you know, when it does, then we'll start worrying about that.</p> <p>H: Well, she maybe has a different perspective than I do. From my point of view, right now, today, we don't have an awful lot to cope with because I'm fully functional and capable.</p> <p>H: We haven't experienced the really bad things yet.</p> <p>W: I...at this point, would have no advice because I don't know what's going to happen.</p>
<b>Making Sense of the Disease Process</b>	<p>H: I told myself, I'm not losing things in my memory.</p> <p>H: I'm the kind of guy that when somebody tells me bad news, I like to know everything I can about it.</p> <p>H: Well, probably a lack of understanding of Alzheimer's. You know, to me just as a layman knowing no more about it than anybody you would just fall off the street and ask questions, I thought that Alzheimer's ...and I know to a certain extent does...but you lost information that was in your memory.</p> <p>[Okay] And my initial, largest initial problem.</p> <p>H: I think we both have a pretty good understanding of that, that ...I mean that it is progressive, that there isn't a cure and that your mind.</p> <p>H: ...well I understand that what's really going on up there is the nerve cells are dying in your brain.</p> <p>H: That's part of the problem that affects you, I think, psychologically, the fact that we not only have read about it and educated ourselves</p> <p>W: Because I really thought his memory would have gone fast.</p> <p>H: I've convinced myself that I am in the early stages, that I do have a lot of good years left.</p> <p>W: I think I'm pretty honest with myself when I look at things that are happening and I haven't seen a lot of things yet where the information is just flat gone.</p>
<b>SOCIAL</b>	
<b>Theme</b>	<b>Descriptive Examples</b>
<b>Role Changes</b>	<p>H: I've been very, very healthy all my life. I've never had any real serious illnesses. I rarely have to take any medication for any extended period of time up until this..., so I've just been really, really fortunate and healthy I think for my age, particularly now.</p> <p>H: But she's the one that will have to take this responsibility.</p> <p>W: But I've never ever had to take care of him...I mean like that and it's always been reversed, like you know, have babies and I mean my family...I've lost most of my family to cancer and so, you know, he's always been there for me. I just want to do it for him.</p> <p>W: I mean, you know...Physically and I've probably always been the one who's had more physical ailments than he...well obviously, he never has had any. I just worry that we're going to be able to get through it.</p>
<b>Marital Impact: Positive and Negative</b>	<p>W: No, we have short tempers at different times and we'd be going through that with us being together as much as we are.</p> <p>W: This was when I was with the kids and then he would forget that we were going someplace or something like that...</p> <p>W: ...and I thought it was because he didn't listen to me when I told him, you know</p> <p>W: ...and I blamed and it caused arguments, not realizing that it was</p>

	<p>something else, but that was my biggest complaint.  W: I do give him a bad time about forgetting. You know, I write notes.  H: I mean, I'm sure she gets tired of me asking her questions that I should know.  H: It's probably...I think it's impacted her more than it has me.  H: She's got to put up with it.  W: Other than that, I think it impacted our marriage. We probably tell each other, we love you maybe a little bit more.  W: Maybe we appreciate....maybe I appreciate him a little bit more than I was showing when he first retired.  W: He'll lose me if I'm saying something or we kind of do this and then we've got to do this or something and he'll say, say that again or what is this we're doing and I'm positive it's because he doesn't listen the first time around.  W: We'll talk. I mean, he'll talk about it.</p>
<p><b>Relationship with Doctors</b></p>	<p>W: I really like them.  W: But the second time, he was very mellow and talked to Don a lot and told him what he really needed to do and for one thing,  W: So I really, really think highly of him.  H: but when I went to see Dr._____, I had pretty much convinced myself that it wasn't Alzheimer's.  H: I mean they've done what they're supposed to do. I'm not unhappy in any way with any of the treatment I've received.  W: The first time I thought he was really right on the line...I mean, I don't want to say abrupt, but he wanted us to tell the story and not elaborate on everything.  W: Anyway, I admire Dr._____ and I really like the Dr. _____ that he went to.  W: I mean...he and Don got to where I thought they were on a really good level of understanding  H: I trust them.  W: I know that they certainly were more in tune with what was going on than the doctors we saw five years ago or four years ago.</p>
<p><b>Normalizing the Experience</b></p>	<p>H: Emotionally, you would think most people would want to know how they're going to die unless something else gets you first.  H: I mean it's going to be a long time. I'm 71 years old and there's a number of things that can kill me before Alzheimer's.  H: There's ....I can't remember the stats I read but something like fifty percent of the people with Alzheimer's are going to die of something else. And you know, that's probably true.  H: I don't think that we are any different than anybody else that would have to go through it.  W: There is not a day goes by that it's not a part of my life, you know. Memory...where if I'm with my kids, they will ask me questions, but they won't ask him.  H: It's probably difficult in any family when you get bad news about a relative.</p>
<p><b>Social Activities</b></p>	<p>H: Physically I'm still great. I mean I play golf....  W: I look forward to golf days because otherwise we're together 24/7. And I love him, but give me one day.  H: We don't go out as much as we used to, so we spend a lot of time sitting there watching the idiot tube and you know, I don't have any problem watching television and you know, if it's a mystery or something.</p>



<p><b>Social Relationships and Support</b></p>	<p>H: People don't want to know it.  H: I don't have a real close buddy that I can...  W: That's the only thing that I can think will change, that I will return some of the stuff that I've been doing for Anne and the rest of us for the last three years, so...we're a pretty tight knit group, that particular group and most of the husbands have all known each other for 49 years or some of them went to school together, you know.  H: Except I'm sure you've talked to Bernie about it. Her husband passed away and the two of them go out to dinner and whatever and they spend a lot of time together...I'm sure they talk about it, but otherwise, we haven't talked to any of the people in our circle.  W: They feel very badly. They know it's a disease. Everybody has said, you know, if you need help, let me know.  W: Honey, when you repeat the same story a fifth time, they know something is wrong.  W: The people that we're with the most probably know less about it than anybody. I mean, we have a regular place where we go and have drinks and stuff and party with friends and I know one couple suspected that he was having problems with his memory, but other than that, it hasn't been too well.  W: Well to be honest with you, we really haven't told a lot of people.  W: And I'm you know, I'm reading too and I am going to go to caregiver's meetings and I will learn  W: I think Cindy in Dr. _____'s office told us to get in touch with the Alzheimer's Association.  W: Somebody that you can talk to is important.  H: That's the caregiver's perspective..... from my perspective, they said I don't need anybody to talk to.</p>
<p><b>Previous Exposure to AD</b></p>	<p>W: In fact, I have lunch with this girl, the one whose husband's family said he gets frustrated with John...did you at the beginning and she said, I still do. So I thought, that's pretty good. That's normal.  W: I'm watching a very good friend hurting her own body by trying to take care of her husband and I know the things that she has to do and I've told him.  W: The only way I can tell you this is this lady that we talk about whose husband is so bad. The group of us started in kindergarten together. There's about five or six and we still ....we go to lunch every other month and so we have known each other all our lives. Anne always says that we are her support group and I am sure that I will get that same kind of support when and if I need it.  W: And we have a friend that we've watched for three years that has gone through very fast.</p>
<p><b>The Kids</b></p>	<p>W: I mean our kids have talked to me about it and they tried to tell me a lot of times what they think I should do but on the whole, it just ...but sometimes...  W: I don't talk about it with my kids anymore because they just say I'm too, you know and so we just kind of ignore it.  W: well we have a daughter that insists that we go to...well he goes to another doctor but that's up to him. If he wants to do that, it's his choice.  W: I don't know how our kids will be. I mean right now, they are so busy with their own lives that you know... they care and they're very concerned about their Dad.</p>
<p><b>SPIRITUAL</b></p>	

Theme	Descriptive Examples
<b>Pondering Faith and Death</b>	<p>H: I really don't know if there's a heaven and a hell. Or do you just die? Whether your soul lives after you're dead, you know, I'm not saying that's all hogwash. I'm just saying deep inside, I don't know.</p> <p>H: I just have a feeling that whatever is going to happen is going to happen. If there are any changes I can make now probably wouldn't make any difference.</p> <p>H: you know, I've heard stories about there are people who find out they're going to die, all of a sudden they get religion and whether that's a play-it-safe mechanism or what, I have no idea.</p>
<b>Believing and Questioning God</b>	<p>W: He's certainly getting questions from me right now.</p> <p>W: I don't think He always listens. (God)</p> <p>W: I know there's a God.</p> <p>W: ...believe me when our kids were little and had all these things, I totally believed that He saved one or two of our kids.</p>
<b>Faith</b>	<p>W: How about me? Oh I believe in most of it.</p> <p>H: Well I believe there's a higher power. I'm not sure. I can't explain to you what that means to me.</p> <p>W: Uhm, I...during this particular disease, I think what I need to believe so that I can ask for support for me physically.</p> <p>H: I didn't say I didn't have any faith....there's a difference between religion and faith</p> <p>W: I believe that you need that in your life.</p>

## Appendix E - Case Two: Complete Themes and Examples

<b>Case 2: Husband has AD</b>	
<b>BIOLOGICAL</b>	
<b>Themes</b>	<b>Descriptive Examples</b>
<b>Knowledge of the Disease</b>	<p>H: Loss of memory I guess.</p> <p>W: That's what I would say, loss of memory and function, body functions to do what they used to do.</p> <p>W: You lose so much of the knowledge on how to do things, how to put things back together.</p>
<b>"He doesn't see it."</b>	<p>W: He doesn't see it, you know in a lot of ways. He's not that far into it, you know, he's just getting on the start of it, I think.</p> <p>W: He doesn't understand a lot of what's going on and it's like I brought it on him and I have no...I don't know how to tell him, you know...it's just something that is happening with him.</p>
<b>Getting Diagnosed</b>	<p>W: I think he's better in a way now than he was because he was on one memory medication and I didn't see any difference in it really, so then she put him on another one and he was just getting started on it and that's when we went down to Nebraska and she had to put him back on this Aricept.</p> <p>W: He was in the first stages....I can't...and they wanted to help whatever way they could, with the medications and the different things to do.</p> <p>W: When we had our meeting down there, you know....</p> <p>W: The first time that I was sure down at Nebraska. My other doctor and I kind of suspected it back and forth but to really have a diagnosis.....</p>
<b>Recognizing Something was Wrong</b>	<p>W: Well, I'd say it's been probably been a year that I didn't really realize that completely, you know...by different things that he would ask me back.</p> <p>W: He just didn't know where he was at and stuff like that, you know.</p> <p>Confusion. [Okay] Where he's always been pretty...like he knew where he was and what he was doing and just the confusion of it.</p> <p>W: Sometimes it's a little orneriness I guess. He tries to aggravate me in some ways you know but I could see it really wasn't that.</p> <p>W: It was just that ...cause I would either tease him sometimes...I already told you that. Don't you remember me telling you that? Pay attention to what I am saying to you.</p> <p>W: That's the thing that really...that made me notice was...I was forever saying pay attention, pay attention and he just couldn't pay attention to a lot of things.</p> <p>W: Even when he was driving or when somebody would say something to him and it would just go up and over his head and I'd say so and so told you that. He wasn't paying attention?</p> <p>W: He was having trouble with dizziness at that time, but he don't seem to be having it now again.</p> <p>W: I know he was really getting real bad there quite awhile before we ever went down there cause I could hardly get him into the car.</p>
<b>PSYCHOLOGICAL</b>	

Themes	Descriptive Examples
<b>Frustration with AD Symptoms</b>	<p>H: That's what she thinks anyhow that I don't pay any attention.</p> <p>W: See, that's the one thing that the boys have all been so upset with him and he doesn't want to pick up on some of that, so after awhile it gets pretty annoying.</p> <p>W: See that's another thing, and that's bothering him and then when we find a solution, then all at once, you don't need it no more so you wonder, is that just an attention getter sometimes or is it just...what it is.</p>
<b>Worry about Future Changes</b>	<p>H: I've known a couple of people that's had it and it's not good too see.</p> <p>W: Well I was just worried about... are things going to get worse, you know, very very forgetful so I couldn't go off and leave him alone.</p> <p>W: When it comes to that time that we can't, then I guess we'll have to go in a senior home.</p> <p>H: Well I don't want to be completely disabled, so I have to have somebody wait on me every time I turn around. What the heck. As long as I can do it, I'll do it.</p> <p>W: ...the rest of your thinking about travel and other things, you know, that you could have done maybe.</p> <p>W: I think I won't be able to read hardly anything again and that really upsets me , so I don't know and then I probably have to get somebody that can take us places if we have to go, you know.</p> <p>W: We'll probably change as time goes on but you know, they've got a lot of medicines out now that ...</p>
<b>Sadness and Confusion</b>	<p>W: A lot of misery I think. It's going to be a lot more.</p> <p>W: Confusion and such. Not knowing what to do.</p> <p>W: No. I just feel sad about it, you know.</p> <p>W: Kind of feeling sorry for myself I guess.</p>
<b>Coping Day by Day</b>	<p>W: Struggling kind of...day by day...Whatever comes up, you just take care of it, whatever you can.</p> <p>W: You just have to take it like they say one day at a time and it comes on so slowly that you don't really realize it.</p> <p>W: What do we do to cope with it? Like I say, day by day, what ever comes up.</p> <p>W: We're just plugging along. We don't know what to expect.</p> <p>W: You just have to take it day by day I think and whatever you think is going to work, that's the way to go.</p>
<b>Feeling Responsible and Lonely</b>	<p>W: And being so responsible until...I mean you can't run to the phone all the time and ask somebody else what you should do yourself.</p> <p>W: I feel kind of all alone in a way.</p> <p>W: A sense of responsibility.</p> <p>W: I can't really talk it over with him cause it kind of goes over his head like it don't mean anything to him, you know, so.....I have to figure it out for myself.</p> <p>W:I have full responsibility of everything, you know</p>
<b>"I didn't know I had a problem."</b>	<p>H: I didn't know I had them.</p> <p>H: You get to be 90. I don't think you're really sharp at everything do you?</p> <p>H: I haven't found anybody yet that's been real sharp.</p> <p>H: I didn't know we had any problems...that's what's bothering me.</p> <p>H: In the first place, I didn't know I had a problem. She says I do.</p> <p>H: Yeah, but at our age, don't some people always have a lapse of memory.</p>

<b>SOCIAL</b>	
<b>Themes</b>	<b>Descriptive Examples</b>
<b>Trying to Help</b>	<p>W: Trying to make him understand that I'm trying to help him in a lot of ways that he doesn't understand.</p> <p>W: He wants to do it himself. He's always been...he's done his own thing.</p> <p>W: But then there's certain things he has a real hard time with and then I'll say, well, let me help you....oh I can do it myself.</p> <p>W: Then I'm done. Do it yourself and when you need me, then you ask me and I think that way, you know, he's not just becoming a cripple.</p> <p>W: Let him do it, but when he needs me, then he has to ask and I'll take care of it.</p> <p>W: I just have to correct him more and get after him more, you know, about little things.</p> <p>W: And try to understand that the one that doesn't have it, is trying to help in every way they can and it isn't always the right way either, you know, cause you get upset.</p>
<b>Social Support</b>	<p>H: I play cribbage on Mondays, a bunch of us and he worked them.</p> <p>W: But we watch tennis together and I don't know a whole lot about tennis either, but baseball and some of that...soccer.</p> <p>W: That's what I say...the people that you really associated with in connections like that...they are really all gone.</p> <p>W: Well the social worker said something about maybe getting together with other people that have the same problems you know, organizations maybe and to call and maybe get somebody that could come out and do some of my housecleaning or something.</p> <p>W: Well we've lost so many of our friends, you know. We used to play cards a lot and get together with a lot of different people and do a lot...</p> <p>W: He plays cards once a week and a lady takes him out to play cribbage once a week and he socializes then.</p> <p>W: We go back once a month to a luncheon but ...once in awhile go visit somebody but not like we used to, you know.</p> <p>W: I try to take him everywhere I go to make him get out of the house because we don't socialize much anymore.</p>
<b>Trying Not to be a Burden</b>	<p>W: I don't want to make them think they've got to be over here taking care of us.</p> <p>W: We're able to take care of ourselves as far as we can.</p> <p>W: Well I don't think any of them ever really mentioned much of it.</p> <p>W: Well I was disappointed in my own kids in a way that they haven't....well my one son just had hip surgery, so he really couldn't be doing anything anyhow.</p> <p>W: You know, I don't try to have them...we try to do things ourselves you know, but...</p>
<b>Questioning Doctors</b>	<p>W: And you know, they're not always right.</p> <p>W: I caught different things that's gone on that I have to question back about once in awhile.</p> <p>W: Well, whether we are getting the right medications and such, you know, from my doctors.</p> <p>W: Well at different times, I kind of wondered.</p>
<b>Negative Impact on</b>	<p>W: Well, like I say I get pretty ornery sometimes. Then I have to preach about</p>

<b>Marriage</b>	<p>this or that, tell him what to do....I'm the head around here the boss.  H: She gets a little perturbed is all.  W: And bossy.  W: And not a partner to talk a lot of things over with, like you used to.  W: I just yell more.  W: You just have to be patient with each other I guess.</p>
<b>SPIRITUAL</b>	
<b>Themes</b>	<b>Descriptive Examples</b>
<b>Values/Way of Life</b>	<p>H: I helped everybody I can....been as helpful as you can get....what else can you do in life?</p>
<b>Affiliation with Church</b>	<p>W: Well, we don't go to church for one thing.  W: I like to watch a program on Sunday morning from Lincoln at that time that I enjoy.  W: I was Catholic before we married and so, I wasn't a real strict Catholic, so I kind of let that slide but our children, they used to go to a little church over here on Blondo.  W: But we're not real spiritual, you know. I wish we were more than what we are. We should go to church.</p>

## Appendix F-Case Three: Complete Themes and Examples

<b>Case 3: Wife has AD</b>	
<b>BIOLOGICAL</b>	
<b>Themes</b>	<b>Descriptive Examples</b>
<b>“I get the salt instead of the sugar”</b>	<p>W: I get the salt instead of sugar.                      W: You probably noticed it before I did.                      H: Since we’ve down here, we’ve noticed it more.                      H: She began to repeat herself or ask questions and things. You’d tell her something and then she’d ask the same question again.                      H: How many times did you ask about, “did you have the egg in”?                      H: Yeah. Try to....she has made cookies sometimes and they’ve been pretty runny and I haven’t been here. She likes to make lots of cookies.                      H: Well right at first she just ...why did she ask me....I just told you that.</p>
<b>Accommodating to Symptoms</b>	<p>H: It just...she’s at a point that we need to work together so that if she wants to bake and she loves to bake, so that she doesn’t get too much of one thing in and not enough of another....the telephone rings and she goes to answer and comes back, she has no idea what she’s done...                      H: She really shouldn’t go up those steps because she finds that hard enough to do.                      W: Somebody put that sign up there.</p>
<b>Getting Diagnosed</b>	<p>W: I just don’t remember exactly when it was or how it was.                      H: And from that point on, that’s when I decided that Mom can’t stay alone if I’m not there and so they decided to give her a thorough examination and everything and after this all kinds of stuff.                      H: Well, I think we diagnosed before the doctor did.                      H: We had a doctor we had for 4 or 5 years there. There was another doctor that we’ve seen once....and we haven’t had any physical exams by her yet.</p>
<b>Experience with Medication</b>	<p>H: Well I don’t know that the medicine has improved it. It’s not too often it improves. We can’t get it stopped, but maybe it can slow up or something. Probably it’s not going to improve too much.                      H: Well we asked the doctor about it cause she was having...repeating herself so much. That’s why he asked questions. He didn’t think she was too bad. But he recommended using 5 mg of the Aricept at first and then after about a year he went to 10 and I guess they’re trying other things too.                      H: Oh it’s been about two years ago when ...the doctor gave her Aricept and...                      H: She’s been on Aricept now for a couple of years. [Okay] But that hasn’t helped so far in improving things, but there might be some other ways.                      H: We probably talked to them three or four years ago and at first he asked me some questions and she seemed to look pretty good so he didn’t give her any medication.</p>
<b>PSYCHOLOGICAL</b>	
<b>Themes</b>	<b>Descriptive Examples</b>
<b>Leaving Home</b>	<p>H: One of the hardest parts, after I got out of the hospital, one son’s wife came up to help us...someone took us around to look at the facilities that we might possible be able to live in, assisted living, whatever, and to think about moving out. That was hard.</p>
<b>“Appreciate what you do have.”</b>	<p>W: Well, for one thing it helps you appreciate what you do have. Because in our case.....since we had the ministry at the nursing home for some time, but on the other hand, it’s kind of scary because we think well am I going to be</p>

	there like them.
<b>Accepting the Situation</b>	<p>H: Well, we just believe the Bible and we believe that the Bible is the word of God and we're willing to accept that.</p> <p>H: You hear people call one another stupid and everything else and it's not that. It's just that her memory is gone and you have to learn to accept that.</p> <p>H: Well, you wish you could improve her memory in some way but you can't.</p> <p>W: Well that it's probably not going to get better. You know, I've had other things happen and they've got better.</p> <p>H: It just takes a while to adjust and be willing to accept things when you have to and just understand and also try to comfort as much as you can.</p> <p>H: The trouble is she just doesn't remember as much as you wish she would remember.</p> <p>H: The fact that she doesn't remember is...I have to understand that she remembers all she can.</p> <p>H: I think it's hard for her to accept it.</p> <p>H: Then I began to realize that she doesn't remember. Then you just have to accept it.</p>
<b>Dealing with the Diagnosis</b>	<p>W: Well, it doesn't make you happy. But I suppose it probably wasn't terribly surprising because my mother had had it, but you know, you just don't always think it's going to happen to you, but you know....</p> <p>H: But an awful lot of things do come through heredity.</p> <p>W: Well, I wasn't happy about it, but what can we do?</p> <p>W: Well probably not real high. But then on the other hand, we're going to fight this. Probably I realize I'm probably not going to get better but at least I'm hopefully not going to get worse.</p> <p>W: It hasn't been too good but I try to stay hopeful. I'm hopeful it will get better, but I have to accept that some things are different.</p>
<b>SOCIAL</b>	
<b>Themes</b>	<b>Descriptive Examples</b>
<b>Understanding and Adjusting Together</b>	<p>H: We just try to talk things out.</p> <p>W: I mean we have a little bit of understanding you know of the other person because you know, it.</p> <p>H: We have to keep working together on things or else we may have problems.</p> <p>H: You just have to adjust and realize that it takes two to fight and it takes two to get along.</p> <p>H: Yeah, we don't fight. You have to try to listen.</p>
<b>"It's best if I help her."</b>	<p>H: I think it's best if I help her so that I can see that she gets all the right ingredients and things.</p> <p>H: She still wants to do things. She doesn't want to just go lay down on bed and stay there the rest of her life. That's why she still wants to make cookies and stuff...I'll have to be by her side to see that she gets all the right ingredients in and doesn't get too much salt...doesn't work.</p> <p>H: She doesn't want to hear it or it's gone, or she's not going to remember it, and you just have to continue to do all you can to help.</p> <p>H: Well I've been trying to help her more than I had before.</p>
<b>Community Support</b>	<p>W: Oh you know, I think it's important to have God's help and also not be too proud to accept other people's help.</p> <p>W: Well we do go to Meals on Wheels but that's just Monday through Friday.</p> <p>H: We've had the Visiting Nurses Association come in and help her with the rehab and so forth and they sent her to another place, well actually it was the</p>



	<p>hospital...</p> <p>W: I know I'm not out as much as I used to be, but I still see a fair number of people.</p> <p>H: Well, we go to church in Council Bluffs. The church family prays for us. We get over there every Tuesday night, we have prayer.</p>
<b>More Time Together</b>	<p>W: We've had more time together because he hasn't...</p> <p>W: Well for one thing, we have more time together.</p> <p>H: I'd say it has made us closer.</p> <p>W: I would too. (Q: How has your marriage been impacted?)</p> <p>H: Even before we were married, we prayed together.</p> <p>H: Every day, we have time of prayer together.</p>
<b>Support from Children</b>	<p>H: Our boys can't help as much.</p> <p>W: Well I think they've done the best they can.</p> <p>W: Well I think, you know, they've tried to be as helpful as they can. Maybe get through more phone calls and things like that.</p> <p>H: Oh I think they want to help as much as they can.</p> <p>W: From our children.</p> <p>H: We have three grandkids. Three of Mary's kids came over yesterday to play games and stuff. (What social support have you received?)</p>
<b>Reaching Out to Others</b>	<p>H: we go up to Life-care center of Omaha. I worked there as an employee part-time so I associate with the people in the nursing home.</p> <p>W: Well you could relate...we still do go sometimes to the nursing homes and you can relate to people the lonelier you are.</p> <p>H: Well you don't want to shut yourself off from everybody. It's a matter of reaching out and sharing what you do have.</p>
<b>SPIRITUAL</b>	
<b>Themes</b>	<b>Descriptive Examples</b>
<b>Relying on God</b>	<p>H: The things that have happened have helped us get closer to God.</p> <p>W: I think so. Yeah.</p> <p>H: We just continue to take it to God and pray more.</p> <p>H: Well, I think our relationship with God. (Q: What has made this process easier?)</p>
<b>Spiritual History</b>	<p>H: We've been pastoring churches for 44 years.</p> <p>W: Well I didn't preach...but I taught Sunday school. We had, at least in those days, the pastor's wife was supposed to do quite a bit of entertaining, you know, like when missionaries came or evangelists.</p>
<b>Trusting in the Lord</b>	<p>H: Thy will be done Lord. Give us wisdom. Give us your guidance.</p> <p>H: We were just coming to the point that God doesn't heal everyone and we pray for her and we put things in God's hands and we don't worry that much about them. We're going to trust the Lord and He'll see us through all these things and if you have God to rely on, he helps so much through life.</p> <p>H: Well, we just believe the Bible and we believe that the Bible is the word of God and we're willing to accept that.</p> <p>H: Seek yee first for the kingdom of God. You know all the other things that we need in our life will be added to it.</p>
<b>Hope Beyond this Life</b>	<p>H: So we have hope beyond this life.</p> <p>W: Well, we believe that God is in charge of our life and that's the way it ought to be. We know eventually things are going to get better.</p> <p>H: But, maybe not in this life. But you see the Lord has showed us by his own self that we don't always have a bed of roses. If we do, they have thorns.</p>

## Appendix G-Case Four: Complete Themes and Examples

Case 4: Wife has AD	
BIOLOGICAL	
Themes	Descriptive Examples
<b>Recognition of a Problem</b>	<p>H: It was actually the school system is the ones that saw that there was a problem.</p> <p>H: Well somewhat but you can't really pinpoint it ... what the problem was.</p> <p>H: They actually recommended that she go see a doctor and the [the school did] that's what got the ball started and here we are now.</p> <p>W: The principal was talking and I was talking like this and he had another lady from the agency...she knows about what goes on in the schools and so....</p> <p>W: Actually that is the way that they thought it would be best rather than to fire me was have me retire.</p> <p>H: ...actually I was over in Iowa when I get the phone call that she is getting forced to retire.</p> <p>W: Kind of toward the end of the school year as I was thinking, deciding whether I was going to teach this year.</p>
<b>Diagnosis Process</b>	<p>W: Uhm, it was kind of hard for me to decide when exactly the diagnosis took place. Because I had been to so many places you know, but I guess I thought that probably it was when we were at Dr. _____ office, that I thought well that must be the diagnosis, you know.</p> <p>W: And I even talked to my gynecologist about it.</p> <p>H: Well, you've got Landis and the one in Norfolk and Creighton, so I'd say three.</p> <p>W: She told her that that would be a good place to go so then we went there. And I guess that's when I really thought that...you know, he gave me a thing where you take pills down to a certain point and then you take the test you know...and then he gave me a prescription for that.</p> <p>W: And then my oldest daughter, Christine, arranged for the appointment with Dr. _____.</p> <p>W: Somebody and my niece, was involved with clinical psychology and she arranged for a cat scan up in Norfolk with a clinical psychologist and so that was probably the next thing after...</p> <p>H: Well that was in what...May? Right at the same time when school got out, so it would be in May.</p> <p>W: Well, it probably was Dr Landis, probably.</p>
<b>Self Recognition of AD Symptoms</b>	<p>W: There are times when I'm talking to a person or something and trying to think of a certain name, you know, something like that. I haven't done a lot of reading. I have some information but uh, and I don't know.</p>
<b>Medication Experience</b>	<p>W: Dr. Landis was the first one to give me samples. And it was the same sort of thing. It was the 5 mgs for awhile and then it was 10 ...</p> <p>W: Well as far as taking the medicines and things like that, that didn't bother me. It was good actually and I didn't have a lot of side effects from one type of pill against the other [okay] and things like that.</p>
<b>Questioning Doctors</b>	<p>H: Yeah. I'm a professional in my field and a doctor that is...a family doctor is a professional too, but he's not a specialist. And that's where we.... You take</p>

	<p>your car to a mechanic, you don't take it to a shady tree mechanic to get it fixed anymore.</p> <p>W: I know that one time though when we were down there....you went with me that time and you said, I don't think we'll do what he said....that was Dr. Landis.</p> <p>H: Well that was because he wanted to put you on...he doesn't....His information was trial and error and he wanted to put her on some pills that I thought, well if we're going to go to an expert, you take the pills now and it may throw things off, so that's why...now that she's with an expert, she can do whatever.</p>
<b>PSYCHOLOGICAL</b>	
<b>Theme</b>	<b>Descriptive Examples</b>
<b>Past and Present Knowledge of AD</b>	<p>W: Well I think somewhere in some of the information that I got, I read that it's a progressing disease.</p> <p>W: My mother had Alzheimer's. So it's genetic, right?</p> <p>H: Somebody says you've got Alzheimer's, I go I don't even live with them, you know...cause back to the days, the aluminum cookware, you know.....</p>
<b>"Take it one day at a time."</b>	<p>H: Take it one day at a time.</p> <p>H: Well for me....life is short, that you think it's long, but life is short and you've got to pay attention to what's going on in order to....you've just got to live your life no matter what happens, you know.</p> <p>H: The same thing doesn't happen every day.</p> <p>H: One day at a time. (Q: How have you been able to get through this experience?)</p> <p>W: I guess whatever happens, happens.</p>
<b>Disappointment</b>	<p>W: I haven't really been disappointed, yeah. (have you been pleased or disappointed with the support you have received?)</p> <p>H: Yeah. And sometimes I feel like I disappoint them more than they disappoint me. But yeah, it's not disappointing at all.</p>
<b>"I'm not the only one."</b>	<p>H: I mean I had to get it off my chest and I find out, well I'm not the only one that's in this world that has that problem too.</p> <p>H: Yeah and if it wouldn't have been for the people at work that I have conversations with all the time, I'd probably would be in the same boat she's in right now.</p>
<b>Worries About the Future</b>	<p>H: For me, am I going to have to stop working in order to take care of my wife?</p> <p>H: Because....well you never know how well you're gonna survive this world, but I'm looking at doing some traveling and traveling with her going about the country. I've got two brothers that are going to resign down in Arizona and I'd like to go across country traveling.</p> <p>H: To me, it's leaving her alone. Because like she says, her mother had it and I had to come over here and do things around the house to make them like child-proof, so that she wouldn't injure herself when her mother was alive and living here. I haven't done that yet to this house for her sake and that's one of the things that I'm concerned about.</p>
<b>Emotions Experienced</b>	<p>W: It's been more comforting to be able to be here.</p> <p>H: Well my attitude was I was upset. Not with her, but just upset period you know.</p> <p>H: Some days, it drags me down pretty hard and other days it doesn't.</p>

<b>SOCIAL</b>	
<b>Themes</b>	<b>Descriptive Examples</b>
<b>Continued Support and Activities</b>	<p>W: Well...I still am able to play the organ at church and that's important.</p> <p>W: And they have an activity club in town that I hadn't belonged to while I was teaching but they have a get together and they sometimes make things, have an activity meeting or something or sometimes they find a place they want to go like Grand Island or go out to eat or go different places and so I can be included in those.</p> <p>W: I went to the high school football games, homecoming football games. I hadn't done anything with the school until and it's about as good.</p> <p>W: You know, like I said, being involved in the groups are good.</p> <p>W: There's lots of people. We have a.....we have a prayer chain in the community so there's about three people that started when somebody called and said we want her for so and so and then we called around so it gets around to everybody and we're praying for that person, you know, and that's one thing that I do. It's called touching for people.</p>
<b>Small Town</b>	<p>H: We've always lived in this town, so...</p> <p>H: Well I would say co-workers, even Anne's co-workers have made it easier because they talk about it all time, wanting to know how she is. The harder ones I don't answer their questions. I just said, well didn't you forget something once before? Well yeah, like yesterday. You answered your own question you know. In a community this size, everybody knows everything about you, so...before you know it.</p> <p>W: I get to be involved with some of the people in the community too. It helps so that's good.</p>
<b>Concern from Family Members</b>	<p>H: The kids were very concerned. My immediate brothers and sister were also concerned that it was related to...I mean the diagnosis...you know everybody said there's something wrong, but they just couldn't put their finger on it.</p> <p>W: I know we have one daughter. They called him and told him he should call me every day so that you know and he does, almost every day, every night.</p>
<b>Closer and Better Marriage</b>	<p>H: Well, it's probably brought me closer to her.</p> <p>W: Well I think it's better, probably better. (How has your marriage been impacted?)</p> <p>H: Yeah, so I spend more time in that aspect. I try to get her involved in more of the things that I do, get her to go down and see my mom more often and then ....she's 80 years old. She's got macular degeneration that was dry, now it turned wet and so she has [she's lost some of her speech]. Anne helps out in that aspect and we're closer in that regard.</p>
<b>More Time Together</b>	<p>H: To cope with the disease? I talk to my co-workers but to....spend more time with her. Now instead of forcing her to cook, I cook or I take her out to eat, you know.</p> <p>H: Well most of my time is occupied at work and so therefore I'm just here like Saturdays and Sundays and it... social-wise, she carries all the weight, so I just support her.</p> <p>H: I want to spend more time with her now. It used to be I'd come home and throw my clothes on the floor and go downtown and spend it with the guys. Now, I still do it, but not as much downtown with the guys. I spend a little bit more time here.</p>
<b>Previous Exposure to</b>	<p>W: And I'm 59. And my mother was in the care home here in town for seven,</p>

<b>AD</b>	<p>seven and a half years before she died.</p> <p>W: My dad was a lawyer and I know there were things that he put somewhere and then they would be put somewhere else, so my mom would change that or whatever so then he got so he found places to hide them, you know and those are the things I remember about him.</p> <p>H: Even some of my close friends have their spouses with Alzheimer's and stuff like that or worse.</p> <p>H: You're treated a little different too. I mean it's not special, but it's just...you can sense it...there's a little bit of difference in the way they talk to you and stuff like that.</p> <p>H: Oh my sisters keep sending....she's a nurse, a registered nurse out of Washington and she works with hospice and she's always sending information down the pipeline to us about it every now and then. She's sent me two books that I know of and to my mother in that respect.</p> <p>W: I was down to his mother's house one day and we were watching a show on EWTN and it was talking about toward the end anyway of Alzheimer's and talking about feeding tubes or something and I was going to ask Betty cause I was trying to remember.</p>
<b>SPIRITUAL</b>	
<b>Themes</b>	<b>Descriptive Examples</b>
<b>“Keep the faith.”</b>	<p>H: You've got to keep the faith. I mean turn it over to the Lord and let Him carry it for awhile, you know. That's the only way I can deal with it.</p> <p>H: Keep the faith. (What approach have you come up with for dealing with the disease?)</p>
<b>Spiritual Identification</b>	<p>W: I go to another thing in town...is I go to the Share Group on Thursday morning and then they also have a Bible Study in the afternoon. Those kinds of things help a lot.</p> <p>W: I'm pretty spiritual.</p>