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The Importance of Early Counseling and Education of Persons Diagnosed with Alzheimer's Disease and Their Caregivers

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THE IMPORTANCE OF EARLY COUNSELING AND EDUCATION FOR PERSONS
DIAGNOSED WITH ALZHEIMER'S DISEASE AND THEIR CAREGIVERS

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B.S. Rehabilitation Services

Southern Illinois University, 2009

A Research Paper

Submitted in Partial Fulfillment of the Requirements

For the Master of Science

Rehabilitation Counseling Training Program

In the Department of Education and Human Services

In the Graduate School

Southern Illinois University Carbondale

August 2011

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RESEARCH PAPER APPROVAL

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DIAGNOSED WITH ALZHEIMER'S DISEASE AND THEIR CAREGIVERS

By

Haley Pottorff Basnett

A Research Paper Submitted in Partial

Fulfillment of the Requirements

for the Degree of

Master of Science

in the field of Rehabilitation Counseling

Approved by:

Stacia L. Robertson, Ph.D., Chair

Graduate School
Southern Illinois University Carbondale
August 2011

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DEDICATION

I would like to dedicate this research paper to my family: my husband Ross, my parents, my grandparents, and anyone else who prompted, cajoled, threatened, cheered, and/or “gave me the look” to complete the necessary requirements for the completion of this paper and for my degree. On a more serious note, I want to dedicate this project to those who have suffered with Alzheimer’s and to those who have been sources of constant support as selfless caregivers for their loved ones. This dedication comes with the sincere hope and fervent prayer that, one day soon, research will find a preventable cause, a reverse, and/or a cure for this disease.

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CHAPTER ONE

Introduction

Currently, 5.3 million people in America have been diagnosed with Alzheimer's or related dementias (ADRD) (Billhartz-Gregorian, 2010). Of those people, 5.1 million are over age sixty-five; the other 200,000 are younger than sixty-five, having been diagnosed with what is called "early onset Alzheimer's." Worldwide, 35.6 million people have some form of dementia with that number expected to nearly double every twenty years (Baldauf, 2010). According to the Alzheimer's Association, one in eight people over age sixty-five has the disease, and a new diagnosis is given every seventy seconds. Researchers expect that, by the year 2050, a new diagnosis will be given every thirty-three seconds. By age eighty-five, one's chances of developing Alzheimer's disease increase to fifty percent (Granello & Fleming, 2008).

Of the eight types of dementia, Alzheimer's is the most common, accounting for sixty to eighty percent of all cases. However, no one knows exactly what causes the disease. In less than one percent of cases, Alzheimer's is linked to a rare genetic mutation that is carried in some families, causing early onset Alzheimer's (diagnosis before age sixty-five), sometimes in people as young as thirty. Although old age is the greatest risk factor in developing the disease, researchers are unable to pinpoint the reason for this particular acquisition (Alzheimer's Association "Facts and Figures," 2010a). New studies show that psychosocial risk factors may contribute to the development of Alzheimer's disease. Persson and Skoog (1996) found that people identifying at least three significant life stressors had a twenty percent chance of being diagnosed with the diseases, as opposed to only three percent for those people who had

not experience comparable traumatic events. These stressors include life-altering experiences, such as the death of a spouse, of a child, or of a parent before age sixteen. Other research has shown that chronic stress may contribute to the development of the disease; and when it combined with biological factors, an increased risk prompts a diagnosis (Granell & Fleming, 2008)

In the United States alone, approximately 19 million people are caregivers to persons with Alzheimer's disease. Depending on the number of people in the immediate caregiving roles, caregivers typically provide about sixty hours of care a week to their loved ones. Because Alzheimer's disease progresses aggressively, ultimately resulting in death, caregivers experience a heightened rate of distress, anxiety, depression, and mortality. In fact, in some cases, the caregiver's health declines more quickly than that of the one with the Alzheimer's diagnosis. In addition, depression and anxiety levels among caregivers are more than double the rates of those for non-caregivers.

Research has shown that people who assume this caregiving role experience a decline in their own personal quality of life: marked increases of sleep difficulty, neglected self-care, reported lower health scores, higher rates of clinical anxiety and depression, and higher morbidity rates. Still, additional research has shown that caregivers involved in Alzheimer's education, support groups, and/or counseling have less distress and strain as well as more favorable health scores, which, in turn, allow them to provide better quality care to their loved ones.

In 2011, the first baby boomers turn sixty-five, which will cause an increase in older-age diseases, such as dementia and Alzheimer's (Billhartz-Gregorian, 2010). Seventy-six million people in the baby boom generation in the U.S. alone account for

twenty-nine percent of the total population. It stands to simple reason, then, that the nation will see an increase in Alzheimer's diagnoses in the next few decades. For instance, 411,000 new cases of Alzheimer's were diagnosed in the year 2000 with the number for 2010 at 454,000. In the year 2010, approximately 5.5 million people were older than eighty-five; but for the year 2050, the estimate for that age group will be around 19 million, a quadruple increase. Therefore, in approximately forty years, around 959,000 new cases of the disease will have been diagnosed. The cohort of people older than eighty-five includes about 2.4 million people with Alzheimer's disease. However, in 2031, when the baby boomers start reaching the age of eighty-five, an estimated 3.5 million people will have the disease. Currently, 5.3 million people have the diagnosis; but, by 2050, an estimated 16 million people will be diagnosed with Alzheimer's disease ("Facts and Figures," 2010a). These figures offer only a bleak outlook at present, unless, of course, scientific research and medical advancements can find a way to slow, prevent, or cure the disease. Needless to say, dementia has overtaken cancer as the most feared disease by the older generations (Billhartz-Gregorian, 2010). Alzheimer's disease has been referred to as "the mind robber," and "the never-ending funeral," a diagnosis that certainly means a prognosis of social death, as well as actual physical death (Fox & Max, 2009).

Background of the Problem

As a result of advances in modern medicine, most people can enjoy longer life with fewer health problems; and, as the "baby boomer" generation reaches senior citizen status, more than ever, people are seeking medical treatment to stay healthy. Over 34 million people in the United States are over the age of sixty-five; however, regardless of

new medical treatments, disability of some degree almost always accompanies increased age (Hayslip, Han, & Anderson, 2008). Alzheimer's disease, the sixth leading cause of death in the U.S., is considered the most feared age-related disability among older people; and with age as its biggest risk factor, it is affecting more people than ever before. While those affected by aggressive diseases such as cancer and heart disease often find effective treatments, others who have Alzheimer's disease face a gamut of unknowns: no known cause, no known cure, few effectively preventative treatments, and, most distressingly, no available treatment.

The characteristics of Alzheimer's disease can be classified in three stages: mild (early stage), moderate (middle stage), and severe (late/final stage). The mild stage is categorized by worsening memory loss and changes in other cognitive abilities. People in the early stages often will get lost or confused, repeat themselves, convey personality changes and poor judgment, and display problems in handling money and carrying out normal daily tasks. Because the decline is not yet significant, many people remain employed and live at home, either with a partner or alone (Granello & Fleming, 2008). It is during this stage that loved ones who will eventually become caregivers notice a change, but they feel helpless in pursuing medical help. Ironically, their actions result from knowledge of extremes: they either lack information on the disease or they possess too much information in that Alzheimer's is irreversible, having no cure, so they conclude that going to a doctor would be pointless.

Studies have been conducted on individuals with Alzheimer's disease for years, mostly concerning the cognitive and physical decline that the disease causes. However, studies on the effects of the caregiving role began relatively recently in the 1990s.

Studies reviewing the stress levels caused by the caregiving of people with Alzheimer's showed that 100% admitted experiencing some type of caregiver burden and strain, thus proving the importance of treatment not only for the individual with Alzheimer's disease but also for the caregiver(s) (Sanders, 2005). The Alzheimer's Association estimates that over 19 million people have a loved one with an Alzheimer's diagnosis. In a caregiving situation, the caregiver spends countless hours and much energy on ensuring that the best, most effective care is administered to the loved one. Because of this, caregivers often neglect their own health and needs, often causing extreme physical and mental health declines in the caregiver, as well (Elliott, Burgio, & DeCoster, 2010).

Significance of the Study

Most treatments and interventions for people with Alzheimer's disease do not put much emphasis on counseling the individual with Alzheimer's. Because of one's declining health and communication skills, most treatments focus only the physical aspect of the disease. The allotted money typically goes to treatments such as nursing care and direct support. With a disease so time sensitive, the most cost- and resource-effective manner to treat the accompanying depression is through medications, not behavioral management. The medications prescribed for mental disorders carry adverse side effects, with the possibility of causing premature death, which makes a bleak commentary to the fact that people with Alzheimer's disease receive little to no assistance in treatment for mental and psychological well-being. Since the early stages of the disease are the longest, utilizing that particular duration of time for counseling is imperative (Granello & Fleming, 2008).

Studies covering five US cities and using 495 participants have proven that

caregivers experience higher rates of depression and distress than those who are not in a caregiving role. In caregiver studies, caregivers experience increased sleep problems, report lower health scores, display decreased health-promoting behaviors and increased illness-related symptoms, and have increased morbidity rates. On the average, older adults experiencing depression rate around fifteen percent; however, the depression rate for caregiving adults is twenty-eight to fifty-five percent. In addition, physical and mental health of a caregiver typically improves after the death of the care receiver. Therefore, current caregivers have lowest overall health scores, compared to non-caregivers and former caregivers (Elliott et al., 2010). These figures indicate that counseling for the caregiver, beginning when Alzheimer's is diagnosed, can greatly increase well-being for the caregiver, which in turn, will increase quality of care for the person diagnosed with Alzheimer's disease.

In a study done on the effects of counseling for people with mild Alzheimer's and their caregivers, those people who garnered the most success for reducing depression had enrolled in therapeutic interventions early on, benefiting from structured counseling, education, and support groups for both the individuals and their caregivers. However, this study reports that counseling interventions are much more successful if both parties attend their own sessions, only later attending some sessions together. Results show that the most effective treatments are those that include individuals and families, that are longer and more intensive, and that are designed specifically for each unique family and situation. In short, interventions need to be specifically tailored in order to be effective (Sorensen, Waldorff, & Waldemar, 2008).

Purpose and Objective of the Paper

Until the various unknowns of Alzheimer's can be identified and prevented, the world's population is not exempt from its reaches, either as caregivers or care receivers. While this writer cannot and does not attempt to solve them, it is the objective of the paper to address the issues that we do currently know and perhaps understand, from after the upsetting news of the diagnosis to the various accompanying stressors, and finally, most significantly in the arena of the successes of counseling.

When people are diagnosed with Alzheimer's, they go through periods of depression simply because the prognosis is eventual and certain death. By the same token, many healthcare professionals and insurance companies with whom individuals and their families must deal take an often cold approach to the diagnosis, considering counseling as a waste of time for a situation in which a physical prognosis is hopeless. In treating the physical aspect of the disease, many doctors do in fact prescribe an antidepressant, which ironically, will exacerbate the physical condition of the person affected, hastening the physical decline. Therefore, while the ultimate tragedy is the sentence of death, the progression toward the final stage is not always addressed in such a way to alleviate the severe depression that results from the gradual inability for self-care and to maintain relationships because of lost memory and cognitive function. Research has shown that caregivers and care receivers often experience the same type of distress and strain and seemingly go through congruent psychological stages (Granello & Fleming, 2008).

Regardless of the bleak prognosis for those diagnosed and for those in caregiving roles, ways to best manage the disease offer a more hopeful outlook. Early detection of

the disease is the best way to manage it; and as research continues, more people are becoming aware of what the disease entails. With lifestyle changes, medication, and some preventative measures, people with Alzheimer's disease can maintain a quality of life for months or even years, especially when counseling is available for both the caregiver and care receiver. Counseling services could make a drastic improvement in the entire scenario, especially since caregivers and care receivers alike can feel trapped in a hopeless situation.

CHAPTER TWO

Overview of Literature

In order to best serve the reader in the appreciation of the need for education and counseling for the individual with Alzheimer's and the caregiver, information concerning the effects of the disease on both parties will be presented first. First and foremost, in order to recognize the need for education and counseling, one must appreciate the situations from which various stressors originate, thus initiating the necessary counseling. In subsequent discussion of stressors for both parties, information from various studies will be presented for the various approaches for coping techniques within discussion of the stages through which the individual with Alzheimer's progresses and of the stages of strain, gain, and grief for the caregiver.

Beginning with the staggering news of an Alzheimer's diagnosis, the entire family can be affected by both the known and the unknown of what is to come (Diseases & Conditions). First and foremost, the individual who has received the diagnosis may delve into a gamut of mixed emotions that may soon lead to depression, urging the need for emotional support and counseling in addition to the usual physical attention. Alzheimer's disease, currently the seventh leading cause of death, is a progressive, irreversible, eventually fatal disease that affects one's brain ("Alzheimer's Fact Sheet," 2010), eventually robbing a person of recognition, communication, and the ability to do once-normal tasks, such as bill paying, bathing, dressing, eating, speaking, or even smiling. With these factors in play, the approximated seventy-five percent of people who have the disease continue to live at home, sparking the need for dedicated caregivers (Hayslip et al., 2008).

People with Alzheimer's disease experience a vast array of emotions and behaviors. Each person's affective behavior is different, and some individuals experience extreme varying behaviors or mood swings. Oftentimes later, in the middle and late stages of the disease, one will become combative and argumentative (Callan & Howland, 2009). While stress for caregivers can be enormous at times, they must remember that the person with Alzheimer's disease did not change his/her personality but, instead, that the disease took away "the person they knew," the traits and behaviors, altering them, often without the person's knowledge or understanding. By realizing that the disease robbed their loved one of their usual personality, caregivers can be more individual and understanding to a negative situation (Sorensen, Waldorff, & Waldemar, 2007).

Usually a spouse, adult child, or child-in-law will assume the caregiving role alone, thus increasing caregiver strain as a result of having no respite. In American families, the spouse is typically first to assume caregiver responsibilities, followed by adult children who sometimes take on the role with their own spouses. According to the National Long-Term Care Survey (1989, 1999), nearly forty-one and one-half percent of caregivers are adult children, and nearly thirty-eight and one-half percent are spouses (Pinquart & Sorensen, 2011). However, even in the cases in which duties are shared, when the care receiver reaches middle-stage Alzheimer's, the required intensive around-the-clock care can create an intense pressure on the caregivers. More often than not, those in the caregiving roles experience heightened stress, a sense of burden, and depression; for these reasons, early counseling for caregivers of people with Alzheimer's disease will not only assist in dealing with the current situation but also in preparing for the future, when the worst part of the disease manifests itself (Callan & Howland, 2009).

Conducted research on the relationship of the caregiver to the care receiver reveals how each of these people analyzes the duties of caregiving. While results showed that spousal caregivers of older adults with disabilities provide more effective support, they also report more depressive symptoms, greater physical and financial burden, lower levels of mental well-being, and higher levels of distress (Pinquart & Sorensen, 2011). Schulz and Beach (1994) reported that spousal caregivers for a person with a disability experience a sixty-three percent higher mortality rate than people whose spouses do not have a disability. Furthermore, caregivers who experience the deepest depression have been found to be least likely to seek help for themselves (Granello & Fleming, 2008). Children-in-law, typically the least likely to assume the caregiving role, report less satisfaction and fewer uplifts, most likely because of a lesser relationship (Pinquart & Sorensen, 2011).

HealthDay News conducted a survey among 524 caregivers of people with Alzheimer's disease, asking them about their main concerns for their loved ones. Forty-one percent of caregivers experienced anxiety about memory loss, thirty-three percent reported concerns over personal safety, and twenty-seven percent worried about their loved ones' confusion. Fifty-five percent of the caregivers reported negative changes in their own health as a result of caregiving, and sixty percent admitted that they felt overwhelmed by the situation. Nearly seventy percent of caregivers were most upset by the cognitive changes occurring in the care receiver (Preidt, 2010).

The importance of early detection lies in the fact that lifestyle changes and medications can slow the progression of the disease, possibly allowing clearer, healthier years for the individual, not to mention less emotional trauma for both the care receiver

and the care giver. Ignorance in dealing with the disease and a general sense of apprehension can cloud judgment in seeking professional advice, often exacerbating the situation when one realizes that time lost in seeking medical attention is competence lost. It is during the first three years of the disease that the most brain deterioration occurs; therefore, by the time a diagnosis is given, the brain is already immensely damaged. Still, when loved ones notice general symptoms and cognitive decline such as memory loss, problems with thinking and concentration, confusion, and social withdrawal, (Granello & Fleming, 2008), they fail to seek immediate help when they suspect symptoms of Alzheimer's disease, due to ignorance of the disease, lack of knowledge about treatments and medications, and the belief that the symptoms are merely normal aging (Hodgson & Cutler (1994, 2003, 2004) as reported in Hayslip et al., 2008). Then, later, those caregivers of Alzheimer's care receivers who failed to seek early medical advice may suffer severe feelings of guilt for not acting earlier, which then creates even more need for counseling (Minorities...Alzheimer's, 2010).

Even while the undetected or undiagnosed disease has begun its course, affective changes in lifestyle can help preserve brain functioning for months or years, adding coherent time to one's life (Buracchio & Kaye, 2009). Since Alzheimer's progresses quickly, catching the disease early gives the family more time to prepare financially, emotionally, and mentally for their loved one's care; and, even more so, it allows caregivers to assist the person with Alzheimer's with the types of changes to alleviate rapid deterioration ("In Brief," 2009).

Moderate or middle stage Alzheimer's is demonstrated through damage to the brain in the areas of reasoning, sensory processing, language, and concise thought

processes. Within this stage, people experience a dramatic increase in confusion and memory loss, eventually failing to recognize family and friends. Because they cannot effectively process new information, they typically can no longer learn new things. Coping with these new developments becomes problematic as they become more easily provoked. In addition, impulsive behavior begins to manifest; and some may experience hallucinations, delusions, and paranoia. Because lucidity in the brain of the individual with Alzheimer's diminishes quickly, the person's ability to communicate effectively with the caregiver is immensely altered. However, the person may be able to maintain quality functioning for longer periods of time, especially if a concerted effort is made to adapt to his or her needs (Granello & Fleming, 2008)...

In this middle/moderate stage of the disease, agitation and frustration may accompany the individual's inability to communicate, causing panic or fear, which further exacerbate effective communication. As with the loss of communication skills, the individual's lost capacity to problem solve will quicken depression and confusion, so nonverbal cues become extremely important for the caregiver to notice. Learning the intention and meaning of particular facial expressions and body movements of the individual allows the caregiver to better control the environment's triggers and stressors, cues that will become more pronounced as the disease progresses. Losing one's independence, experiencing medicinal side effects, confusion, and fatigue from sleep changes all play a role in causing unease in the care receiver; being able to decipher certain communication techniques will allow the caregiver to better meet the individual's needs and reduce triggers for agitation and frustration. Finally, within the last stage with such brain deterioration, the duration of inability to communicate with others can vary,

but, eventually, death occurs (Granello & Fleming, 2008). Considering both the dynamics of the disease and the aforementioned statistical information, one can understand the impact it has on the mental and emotional pitfalls it produces in the caregiver (“Alzheimer’s Fact Sheet,” 2010). Again, this emphasizes the progression of stress within the lives of caregivers as the disease progresses within the lives of the individuals with Alzheimer's and the conduciveness of coping techniques for all involved.

Defined as a “behavioral or psychological effort that aids in tolerating and/or reducing the impact of a stressful occurrence” (Cooper, Balamurali, and Livingston, 2007), a coping technique allows the maintenance of good mental health during the caregiving process. Cooper et al. (2007) found that caregivers of people with dementia experience vastly increased rates of anxiety (ten to thirty-five percent) and depression (ten to thirty-four percent). In a study done on coping strategies used by caregivers, researchers found that people who used emotion-focused strategies were typically less anxious and depressed. On the other hand, people who coped by using problem-focused strategies only increased their anxiety. That may be due to the fact that people who use problem-focused techniques work to find resources to benefit the person with the disability and, in turn, fail to recognize or to confront their own coping difficulties. In order to effectively manage psychological well-being, a caregiver needs to find a balance between the two types of coping techniques. Problem-focused techniques are useful when a situation is changeable, one in which a problem needs to be fixed. However, emotion-focused techniques are superior when acceptance is needed. Anxiety is increased when a person attempts a problem-focused technique on a situation that is

unchangeable. By combining the two types of strategies and recognizing which type should be used in certain situations, caregivers can sustain a level of mastery over the situation, thus keeping unnecessary levels of anxiety and depression at bay (Cooper et al., 2007).

Usually, when people enter into counseling in the early Alzheimer's stages, most of the focus is put on preparation only for the later stages. In fact, most early interventions fail to include the person with Alzheimer's altogether. The study reports that, since perceptions of the disease differ between the person with the diagnosis and the caregiver, interventions and treatments need to be geared specifically to each person in his or her particular role. In addition, while research on caregiver burden is relatively new, many studies report the same conclusion: Caregivers greatly benefit from counseling throughout the caregiving experience, from diagnosis until after the care receiver's death. Understanding the trajectory of the disease helps the person with Alzheimer's and his/her caregiver to choose more effective interventions and treatments, thus resulting in a potentially higher quality of life for everyone involved in the life of the loved one. Education and early counseling not only will help the caregivers in their current situations, but they will also equip them with the necessary knowledge, skills, and strategies to more effectively adapt to the progression of the disease (Sorensen et al., 2007).

Research has been conducted on the various types of activities which can most effectively preserve healthy brain functioning for people with dementia. This new plan includes studying the Bible and Shakespeare; at first consideration, this practice may seem anti-productive since many people find the language of the Bible (the King James

Version, especially) and Shakespeare laborious at best. However, once readers adapt to the style of the language, they find that the literature is not unlike music in its pattern and rhythm and may offer the same type of “therapy.” Because a healthy body can help both the caregiver and care receiver avoid other issues to deal with, guidelines for implementing a low cholesterol/low glycemic diet show promise for a healthier brain as well. In addition, a relatively low intake of caffeine has also been proven to help memory functioning. Doctors also encourage individuals to schedule activities during the day so that they stay busy, such as exercising at least thirty minutes a day (“In Brief,” 2009).

A caregiver who has not received any education on coping strategies can miss out on several rather simple steps in reducing stress in their own lives. In the early stages, keeping a loved one engaged in familiar activities may help improve the ability to remember, to make decisions, and maintain fine motor skills as long as possible. Shared activities such as reminiscing over old family photo albums or over familiar, favorite movies or music gives the care receiver the opportunity to discuss the past, often creating a sense of security. Engaging in crafts or in a long-established hobby may also help in hand-eye coordination; and, listening to music or watching a musical can stimulate a sense of well-being. Common sense will dictate a need to “get out of the house.” The enjoyment of the sights, sounds, smells, and touches of nature can provide much needed physical exercise and fresh air, all of which can stimulate verbal skills (Keeping the loved one engaged).

After age thirty, a person does not exercise as much as he/she used to; furthermore, a person’s normal capacity for learning new things daily markedly decreases as the brain ages. Therefore, exercising one’s brain and one’s body can help retain

functioning for longer periods of time, even more significantly for one who has been diagnosed with Alzheimer's. Since intellectual stimulation is very important, doctors recommend learning new activities, such as juggling or playing a musical instrument (Billhartz-Gregorian, 2010). In addition to these coping techniques, doctors greatly recommend for individuals to enlist in clinical trials. Because Alzheimer's has no known treatment, clinical trials are a worthwhile gamble, especially at an early stage, which may also offer a less stressful quality of life ("Alzheimer's Fact Sheet," 2010).

Restructuring the environment is a way which a caregiver can better control the triggers and stressors for agitation and frustration in the life of a person with Alzheimer's; and in the process, can alleviate his/her own frustration within the household or day-to-day practices. Because confusion is a main facet of the disease, keeping one's environment simple and orderly can eliminate such episodes of confusion. Closing off extra rooms in the house, in order to keep the living space as small as possible, will reduce the possibility for excessive stimulation, which is detrimental to a clear mind. Controlling the simplest details, such as paint color, décor, and family photographs (especially in the later stages) can help immensely. When a person reaches extreme forgetfulness, as in the last stages, he/she may not recognize certain mementos or family photographs, thus causing the person to believe he/she is not at "home." Some professionals suggest eliminating extra decorations, trinkets, and pictures, in order for a caregiver to reduce confusion on the part of the care receiver; therefore, keeping a clean house with neat counters, shelves, cabinets, and drawers is a way to minimize confusion (Granello & Fleming, 2008).

Losing depth-perception skills is another issue experienced with the disease. A person with Alzheimer's has trouble distinguishing flat floors from steps and ramps, which is exacerbated by bright lights or glares. Additionally, patterned flooring and carpet may trigger falls and cause injury. If a caregiver can keep flooring simple, eliminating uneven surfaces, then a care receiver can possibly maintain his independence for longer periods of time. Also, researchers recommend not having background noise during a conversation. Having only one person speak at a time allows for better concentration on the part of the person with Alzheimer's. Efforts made to control stimuli in the environment can result in better focus and attention for the individual, thus reducing confusion (Granello & Fleming, 2008).

Even with the positive outcomes from such shared activities, the time to plan and execute these sessions can require even more time in the caregiver's schedule. Therefore, the care responsibilities become more intensive so caregivers harness even less respite time. In the rare occasions when caregivers do have time for themselves, they can never fully escape the situation because the disease and its impact are all pervading. Constant worry and fear make a person feel trapped within him/herself. Life stressors and conflict, directly or indirectly connected to the disease, add to the weight of guilt, as well. Typically, demands from other roles and responsibilities build up and cause intense stress for a caregiver. Systemic issues are a large cause of frustration and grief for a person in the caregiving role, and naturally, caregivers feel that they give the highest quality of assistance. Because the caregiver's life is now fairly little his/her own, time is of the essence, especially when dealing with health professionals who they feel are inadequate. In dealing with the healthcare system, many caregivers report feelings of intense agitation

because they are unable to get straightforward answers or to trust another's judgment (Sanders et al., 2007).

Oftentimes, people fail to see the importance in counseling the person with the disease, perhaps due to the erroneous belief that the individual cannot possibly benefit from it. This pervasive attitude is compounded by the belief that the person with the disease may not be able to communicate or that time and resources need to go toward medication or relaxation instead, all of which may be active determinants in the often excluded implementation of much needed counseling. However, Whitlatch et al. (2005, 2006) found that individuals in the early stages of the disease were able and willing to effectively communicate values, preferences, and concerns about current and future care, thus proving that people with moderate Alzheimer's disease are able to actively participate in their own treatment, both current and for the future (Sorensen et al., 2007).

Currently, the most practiced treatment for persons with Alzheimer's is medication to slow rapid decline. However, a Danish Alzheimer Intervention Study (DAISY) involving three-hundred thirty couples tested, over a six-month period, the effectiveness of an intervention program in conjunction with the person's medication. Researchers collected data which was reported from both the person with Alzheimer's and the caregiver, making each counseling strategy individualized according to various needs within specific roles. The five main components of the study were comprised of the following: 1) individualized counseling for the person with the diagnosis and the partner(s), 2) education for groups of persons with Alzheimer's with a maximum number of twelve participants, 3) education courses for caregivers held at the same time as the partner's group's time, 4) outreach through telephone counseling, and 5) log

books/journals kept by each of the individuals involved in the study. Each component was assigned to the caregiver, the individual, the individual and caregiver, and the entire family/support system. This study showed that the parties who participated had experienced such rewarding success that they sought permanent activity and counseling, respectively, following the study (Sorensen et al., 2007).

By creating multi-faceted treatment plans, health professionals were able to more successfully meet the various needs of more people. The people involved in the study reported that the most helpful component of the intervention plan was the support groups in which they learned self-esteem and coping skills, feeling accepted by their peers. Although some subjects reported negative aspects of the counseling, education classes, telephone hotline, and journals, no one reported negative outcomes of support groups. Everyone reported that the support groups equipped them with the skills to be open and honest about their situations. The care receivers admitted they felt attending the sessions alone was much more beneficial than having the caregivers attend with him. One individual expressed that “it was very nice in the groups” and that he “would like to continue in that group because there [he didn’t] feel stupid (Sorensen et al, 2007, p. 447)” when forgetting words or saying something that may have otherwise been misunderstood. Many reported that being in a group of their peers built their confidence and allowed them to express their own worries and frustrations. This study’s intervention plan also helped the subjects to be more open about their stress and anxiety, thus allowing them to better communicate with family and friends (Sorensen et al., 2007).

Throughout the intervention, caregiver education was broadened by regular contact with a professional counselor. When caring for persons with Alzheimer’s, all

caregiving spouses experience a role change when they must assume the others' responsibilities in addition to their own duties. While many considered this a stressful situation, others simply accepted this as a development that any aging couple must expect within marriage. Through the intervention education, one particular caregiver said that she now had the information she needed, all within a book if she did not now already know the answers to her questions. She was appreciative that she did not have to go search for information herself, thus saving her invaluable time when she needed to be doing something else. Most importantly, for her own sake, she had "learned to take care of [her]self and how to preserve energy" (Sorensen et al., 2007, p. 447) in addition to taking a break without feeling guilty (Sorensen et al., 2007).

Another reported result shown by the DAISY study revealed that caregivers learned an appreciation for the behavior changes in the individual without taking personal offense. Many times caregiving spouses misunderstand and inappropriately react to altered behaviors. The counseling taught them not to interpret these behaviors as signs of neglect or inattentiveness on their part. They learned to control stress and temper in these situations by considering the circumstances in addition to applying what they had learned in the intervention by using coping tools. One caregiver in the study stated that she recognized now that her husband has a real disease; and that this realization has made it easier for her "not to be stressed by his reactions" (Sorensen et al., 2007, p. 448). Through these tailored interventions, social supports were strengthened, and perceived caregiver burden was reduced (Sorensen et al., 2007).

When caregivers are educated on the truths of Alzheimer's disease and what to expect within the unexpected, they become more effectively armed mentally and

emotionally to manage strains of the caregiving role. Equipped with support systems such as the aforementioned interventions, caregivers can more effectively deal with situations that can otherwise be overwhelming, especially when one person is the primary caregiver. Within the confines of this role, however, caregivers have reported positive outcomes, often called "uplifts" (Kinney, Stephe, Franks, & Norris, 1995, as reported in Sanders, 2005) or "gains" (Kramer, 1997, as reported in Sanders, 2005) which "could be helpful in reducing negative affective states" (Rapp and Chao, 2000, as reported in Sanders, 2005). A study conducted on caregiver strain and gain found that, while one-hundred percent of people experienced some type of strain as a caregiver, eighty-one percent reported strains and gains, with only nineteen percent reporting only strains. For the purpose of this study, "gain" is defined as "the extent to which the caregiving role is appraised to enhance an individual's life...Gain may include any positive affective or practical return that is experienced as a direct result of becoming a caregiver" (Kramer, 1997, p.219).

Gain is also referred to as satisfaction, uplifts, and rewards (Sanders, 2005). Kramer (1997) stated that measuring gains in one's role is vital for many reasons. Caregivers want and often need to talk about and share their positive gains with others. Also, a higher quality of care being provided may be directly related to positive caregiving. Finding positive aspects in a somewhat negative situation can alleviate caregiver burden and strain, allowing healthier psychological well-being. Most often used for the Alzheimer's disease population is the support group, a collaborative effort of people living with Alzheimer's, geriatric professionals, and caregivers. Support groups can be located almost everywhere for people to meet and network with other caregivers,

many of whom are adult children in the aforementioned “sandwich generation,” who may experience a high rate of depression as well (“Facts and Figures,” 2010a). Most communities have an Alzheimer’s Association chapter which provides many useful resources and services for people with the disease and for their caregivers. Through the Association, one can gain education, support, respite care, information on medications and various treatments, information on doctors and legislation, counseling, and peer support groups (Granello & Fleming, 2008).

One aspect of Alzheimer's disease that is often overlooked is that it is no respecter of persons. It can affect anyone regardless of race, religion, color, creed, social or cultural situations. But, the impact it has on caregivers among different cultures can vary greatly. People of Hispanic backgrounds report the most caregiver burden and distress, followed by Caucasians and then African-Americans. Research shows that much of caregiver burden comes from *perceived* (emphasis mine) caregiver burden, which means social and cultural roles have a large effect on one’s attitude toward a caregiving role. In the African-American culture, higher levels of mastery are associated with poor health outcomes. Possibly because the African-American culture places greater importance on family and caring for loved ones than do some other cultures, some caregivers in this category reported that assuming the caregiving role was a natural choice, one that needed no consideration. Oftentimes, caregivers say they felt they were the sole person for the job, never having given the decision a second thought (Elliott et al., 2010). In Asian families, the responsibility of caregiving falls to the child-in-law of the person with the disease. In all other cultures, primary caregiving roles are held by spouses and children (Pinquart & Sorensen, 2011). These examples go to the heart of the culture and social

norms that play a large part in one's attitude toward and outlook in a situation. People from cultures who are expected to and who naturally fill the roles to care for their elders naturally experience less strain and burden. On the other hand, for those people who have not planned or expected this role to "disrupt" their lives, becoming a primary caregiver can be quite a shock, developing into the perceived caregiver burden (Elliott et al., 2010).

In a study on caregiver depression and burden involving eighty participants, researchers found that personality type and anxiety over their own aging were the strongest predictors of caregiver burden. A person's perception of the caregiving role greatly affects how the experience will be. Other factors include perceived lack of social support, attributions of causality and blame, and worry over their own health and aging. The findings of the study suggest that by implementing better self-care practices, finding meaning in aging and caregiving, and building a strong social support, the caregiver can maintain better physical and mental health. The same study reported that caregivers who reported higher social support also reported lower depression and anxiety and higher life satisfaction. For older spouses and adult children who would assume the caregiving role, early education is key to a smooth transition. Education and anticipation of Alzheimer's disease's trajectory and of the potential stress and burden for the caregiver will allow for increased mental and emotional preparation that is vital for assuming caregiver demands. By learning what the disease entails, learning effective coping strategies, and familiarizing oneself with community resources, the caregiver (either potential or active) will experience a smoother transition into the role. People with introverted personalities or people who tend to place blame (attributional causality) tend to have higher depression

rates. Changing one's outlook and finding meaning in aging and caregiving will allow a person to feel mastery of the situation, thus increasing self-esteem and decreasing perceived burden (Hayslip et al., 2008).

In a meta-analytic comparison of strain on caregivers, results showed that spousal caregivers experience the highest rate of distress, possibly because the spouse typically has the most prevalent attachment to the care receiver. Impending death of a care receiver is most difficult on his/her spouse, since they are and have been each other's main source of support. Because spouses provide the most hours of live-in care to the person with the disease, receiving the least amount of respite time, they experience higher distress. However, caregiver burden can potentially be reduced if the spouse is able to have some respite time away from the care receiver. As for adult children, most of the stress experienced comes from having to juggle conflicting responsibilities, such as a career, children, and the caregiving role. They report more depression as well as more uplifts (which will be discussed in more detail in the next section). In this case, depression would be caused by their loved one's declining health, and the uplift would generate from the fact that the caregiver feels good about reducing and easing loved one's suffering. Often, adult child caregivers feel that they're reciprocating their own parents' love and care that was bestowed upon them during childhood. Some adult children-in-law experience low rates of distress, because of the lessened attachment to the care receiver. This study also showed that children-in-law provide less help and care than spousal or adult children caregivers. Children-in-law that experience increased rates of stress typically gain less satisfaction from providing care to someone else's parents. The caregiving experienced can be more satisfactory if the child-in-law strengthens his

relationship with the care receiver. The caregiver will experience heightened strain if family disagreements occur. Typically, arguments occur over the way in which care is being delivered to the receiver. Family therapy and has proven to be very effective in settling disputes and providing more effective care to the family's loved one (Pinquart & Sorensen, 2011).

Research involving forty-four spousal and adult children caregivers has found that caregivers of younger people with Alzheimer's experience even more anxiety and distress than other caregivers. They also reported feeling less social support and tended to blame themselves for their loved one's disease. Especially in these cases, coping strategies and stress relieving techniques are invaluable to maintaining good mental health. Younger caregivers for younger care receivers experience more anxiety, frustration, worry, and guilt than spousal or older caregivers, thus decreasing their quality of life. The researchers in this particular study believed that too much knowledge about the disease is detrimental to the caregiving process in that, in a person's anticipation of the disease's trajectory, he will become more anxious and depressed about what stages are to come. Acknowledging that Alzheimer's has no cure coupled with the debilitating nature of the disease leaves many caregivers feeling helpless regardless of how much care they provide. By both focusing on positive aspects and finding meaning in the caregiving process instead of dwelling on the negative stress and burden, one can maintain a more beneficial outlook on the relationship with the care receiver. Factors such as bonding, returning love and favor, and finding inner strength are positive ones that can emotionally strengthen the caregiver (Hayslip et al., 2008).

The purpose of studying gains in Alzheimer's caregiving roles is not to minimize

the severity of the disease and its effects but, instead, to highlight existing positive outcomes. Quality of life and quality time with a loved one with Alzheimer's can be extended when effective care is provided, which is more likely to occur when the caregiver feels successful in his/her role. Researchers found that between fifty-five and ninety percent of caregivers of older adults experience positive outcomes. This figure, however, is for the general older population and not for with Alzheimer's disease, in particular, which is typically graver than other age-related disabilities. Rapp and Chao (2000) stated that "reducing the appraisal of strain and increasing the appraisals of gain could be helpful in reducing negative affective states." While stressors are indicators of strain, they are not indicators of gain. Instead, gain is associated with socioeconomic status, education levels, social resources, satisfaction with social activities, and physical health status (Kramer, 1997b).

Caregivers of certain ethnicities experienced more gains as did people with lower education levels. Older caregivers experience more gains than younger, perhaps due to the fact that younger caregivers have more conflicting role responsibilities. Gender may also play a part in whether a caregiver experiences strain and/or gain. This qualitative study revealed that husband caregivers experience the highest amount of strain, followed by daughter caregivers. Husbands also report the highest levels of gain, followed by wives, then daughters. Sons reported the lowest amount of strains and gains. It is significant to note that all of the nineteen percent of people who reported only strain and no gain were caregivers that provided assistance in isolation, with no respite care or secondary caregivers. Three themes fell under the strain experience category in this study. One such theme is categorized by worries and uncertainties that accompany the

caregiving responsibilities, exacerbated by the caregivers' realization that they have limited control over the situation without the ability “cure” their loved one. Another aspect of strain is the double-faceted worry about alternate care while the care receiver is in the course of the disease and about the Alzheimer's disease prognosis when the uncertain future is considered. The second theme of balancing multiple demands may most often affect adult caregivers, typically in the "sandwich generation," because they have responsibilities of taking care of the parents while having children at home. Often, coordinating schedules and having to switch roles take a heavy toll on a person in this situation. Some people have reported that managing schedules is more stressful than the actual caregiving aspect. The immense strain of feeling overwhelmed with the many aspects of caregiving and the increasing responsibilities that come with a progressive disease comprise the third major theme. The worsening condition and constant decline of the care receiver force the caregiver to face mortality and accept it (Sanders, 2005).

Several positives emerge for caregivers when they experience and report gains. Kramer (1997a) argued that gains evoke caregivers' desire to share and discuss, not only with their own support systems but also with healthcare professionals. These professionals involved within caregiving systems can then use that information to implement "suggested positives" (quotations mine) with others, including those who share caregiving roles with nursing facilities. In addition, when those uplifts or gains are realized, the caregiver becomes more confident and knowledgeable administering techniques learned either on a personal care basis or through support intervention and counseling. Finally, when techniques show positive promise and affective gain, they are more likely to be further examined within the realms of caregiver strain (Sanders, 2005).

Morano (in press) found that caregivers who accept their caregiving roles allowed for more satisfactory life satisfaction within more pronounced feelings of gain (Sanders, 2005). Once that hurdle is overcome, caregivers can more easily appreciate time as opportunity to enjoy togetherness rather than fighting against the disease's negatives. Butcher et al. 2001 asserted that moments of gain resulted from "focus[ing] on and enjoy[ing] those aspects of their relationships...that are still intact (Sanders, 2005), with caregivers often enjoying rewards stemming from an obligation to provide care (Murray, Schnieder, Banerjee, and Mann (1999) as reported in Sanders, 2005), almost as if they are seeing the manifestation of wedding vows to "love, honor, and cherish, in sickness and in health." Because caregivers who experienced these gains found greater social supports (Cohen, Gold, Shulman, and Zuccherro (1994) as reported in Sanders, 2005), more than likely they experienced fewer feelings of isolation than those who reported feeling only strain.

The other major part of this study involving eighty-five caregivers was the themes related to feelings of gain. Eighty-one percent caregivers reported some form of gain in their lives as a result of the responsibilities of being a caregiver. The first major theme that people reported was spiritual growth and increased faith. Needing reassurance, patience, and fortitude, many people heavily relied on God during such a difficult time, feeling a stronger bond and closer relationship to God. Reports showed that people credited their faith with giving them the strength to brave the strains. Others confessed that, while they had not practiced religion in years, being put into such a trying situation led them back to a spiritual relationship. For people who have faith, it is one of the only stable, unchanging factors in a world full of uncertainties. Because these caregivers felt

invigorated by their own spiritual walks, they were more apt to be able to help other caregivers whom they considered to be worse off than they, thus harvesting additional gains (Sanders, 2005).

Because many said they were forced to re-evaluate their own lives and assess their own priorities, they realized personal growth and emerging once-hidden inner strength, the second major category of gain. Constant envelopment by others' more pressing needs often allows one to fully appreciate where his/her place is in the grand scheme of things. In the use of colloquialism, these same people could say that, until the individual with Alzheimer's needed care, they "didn't know they had it in them" (quotations mine) to meet such a challenge head on and survive. Throughout caregiving, they soon realized facets of strength within their personalities that they never knew existed before; some were able to more easily re-evaluate priorities and reassign values to their appropriate places, themselves becoming less self-centered and becoming more others-centered in the process. Several caregivers began noticing that the gains from the caregiving experience extended into other areas of their lives as they became more responsible and stronger, able to more efficiently set boundaries and realize a renewed self-awareness. One of the most rewarding feelings was one of peace (Sanders, 2005), which would naturally be emphasized in conjunction with counseling and intervention techniques.

Accomplishments and mastery constitute the final major theme of gains. Many people reported feeling personal accomplishment in executing tasks that they never before thought were possible. While many might say to themselves that they could "not do this or that," they found themselves doing the particular task anyway, realizing that

they, in fact, had the ability and, eventually, the desire to continue. One caregiver reported that, after caring for her mother, she could "now look at the world differently. Life is short and no promises are made" (Sander, 2005, p. 69). Because this confidence boosted even more when they learned completely new tasks and skills, many even considered career changes which would allow them to care for people. While some considered professional healthcare services as a new career venue, others more specifically stated a desire to share helpful coping techniques as counseling for other caregivers in the way of "instant activities" or "step-by-step guidelines for coping with caregiving" (Sanders, 2005).

Literature on bereavement has shown that extended grief symptoms cause a substantial decline in a person's physical and mental health. Feelings such as yearning, bitterness, emotional numbness, shock, diminished sense of self, mistrust of others, problems accepting loss, and avoidance of reality are all direct effects of lengthened grief exposure. However, because grieving is a natural response to the perception of loss; and because most people do not realize they are experiencing it, the prolonged exposure is natural. Doka (2004) stated that grief is "the constant, yet hidden, companion of Alzheimer's disease and other related dementias." Pre-death grief is caused by the perception of loss, which can be triggered by the decline of the care receiver's recognition and communication, which prevents any type of closure for the caregiver. This phenomenon is referred to as "ambiguous loss" and "dual dying," because the caregiver mourns the loss of the loved one before an actual death occurs. When the essence of a person's personality is taken, the true form of the person is gone, thus sparking mourning over the loss. Even when a care receiver is still living, a caregiver

may not recognize the person as the one he/she used to know. This, however, does not make actual death any easier to handle (Sanders, Ott, Kelber, & Noonan, 2007).

The process of grieving during a progressive illness is called “anticipatory grief,” which is caused by the knowledge that death is impending (Jacinto, 2010). Along with the progression through stages until death comes a variety of emotions and suffering on the part of the caregiver. A person in this role must be able to dedicate part of his life to caring for a declining loved one. Therefore, no emotional experience is unreasonable. Meuser & Marwit (2001) found that grief is different between spouses and adult children. In the early stages of Alzheimer's, the adult child caregiver's grief is demonstrated as denial of the diagnosis. In the middle stages, it is presented as frustration, burden and sadness; and in the end stages, the grief is shown as sadness, longing, and loneliness. In caregivers, grief worsens as the disease progresses, so techniques are imperative for controlling grief throughout the entire caregiving course (Jacinto, 2010).

Several themes are categorized under the experience of grief. In yearning for the past, one signifier of grief, many caregivers wish for previous aspects of their relationship with the care receiver. Hoping for normalcy to return, they are devastated in the drastic changes that have occurred in their lives, longing for a sense of control and for their past goals and dreams to be reached. Another theme that accompanies grief is regret and guilt. Because the caregiving role can be extremely taxing on a primary caregiver without some type of support system, many caregivers find themselves feeling guilty when the situation tests their patience and they lose their temper. The regret can also be retroactive, so to speak, when the caregiver realizes, after a diagnosis has been made, that the individual's earlier and often repeated and unintended provocation effected

squabbling between them. Furthermore, guilt from the caregivers' concerns that they are providing inadequate care to the loved one worsens by thoughts of previous promises made in the marriage between spouses that neither would admit the other into a nursing home, even when healthcare professionals encouraged the transition from home to a nursing facility. However, while the placement of people with a disability comes from pure intentions, seeking more effective care than a caregiver is able to bestow, the guilt over broken promises affects many caregivers in a profound way (Sanders et al., 2007).

Another facet of grief is the feeling of isolation. Having once considered the care receivers as their main source of social support, many caregivers feel intense isolation in the perception that the support is gone when communication drastically declines. This isolation is often aggravated when friends and acquaintances on the “outside” of Alzheimer’s are apprehensive of the disease, often withdrawing from people who assume caregiving responsibilities, thus causing caregivers to feel stigmatized by their outside supports/friends over the care receiver’s diagnosis. Many caregivers reported feeling restricted freedom when they felt they had no escape or respite time. Some reported that their other relationships greatly suffer and they wish they had time to rebuild them or to simply take time for themselves. Because caregiving is highly demanding, most are unable to make plans or to be spontaneous (Sanders et al., 2007).

Confronting and dealing with feelings of grief is usually done on a personal level; therefore, the technique used needs to be specifically suited to the individual for optimum results. In a study using forty-four spouses and adult children of individuals with ADRD, participants from various support groups sponsored by the Alzheimer’s Association, memory clinics, community support networks, and extended care facilities reported levels

of grief within the caregiving role (Sanders et al.). The most popular coping technique in this study was spiritual faith. Many caregivers reported that they felt their role would be impossible if it were not for God's help. They reported that a prayerful relationship with God availed much hope and peace that God's will prevailed, alleviating feelings of being alone and isolation. Another reported successful approach was family, friends, and support groups, all of whom became outlets of sharing and cooperation among people with common frustrations and concerns. Caregivers disclosed talking openly about emotions within the support group helped them to feel less isolated, realizing that they were not alone since many other people were in the same situation. This study showed that forty-eight to sixty-four percent of caregivers experiencing grief attended support groups, and fourteen to eighteen percent participated in professional counseling. The third effective coping strategy was the unconditional love from a pet. Having a pet helped to offset isolation and loneliness, giving a person a solid purpose, especially in recalling that the loved one with Alzheimer's had had a special bond with the pet as well (Sanders et al., 2007).

Grief counseling is most effective when paired with one's successful coping techniques. Counselors should gear their interventions around what stage the caregiver or care receiver is in. One must remember that not giving answers or effective care only increases the frustration felt by all parties. People who experience loss, either perceived or actual, must go through a period of redefinition. Loss affects spouses most dramatically because their role in life must be reorganized. Typically, interests and social supports were shared with the care receiver, so friends, hobbies, goals and the marriage role must be re-evaluated and altered (Sanders et al., 2007).

Depression rates of caregivers with people with Alzheimer's disease and related dementia are much higher than those of non-caregiving adults. However, former caregiving adults show a lower incidence of depression than current caregiving adults, mainly because the psychological well-being typically improves after the death of the care receiver. Although a sense of normalcy is restored by degrees to the caregiver, lingering feelings of grief and regret remain. When the progression of the disease robs the ability to effectively communicate, the chance of closure is diminished. Therefore, when the care receiver dies, much unfinished business remains. Regret over the adequacy of care may set in, and former caregivers may wonder if they did well enough (Jacinto, 2008).

Researching a model of self-forgiveness, a study showed that feelings of unfinished business can be worked through if one is able to foster compassion, generosity, and love toward oneself. Self-forgiveness is the end result when people are able to work through grievances with themselves. The Human Development Study Group (1996) reported that self-forgiveness is extremely difficult because the concept of self-compassion and reconciliation is usually difficult for a person to understand and apply to his/her own life. In addition, because many people feel greater forgiveness from others, they may have trouble applying forgiveness to their own life. However, because forgiveness in its true form is related to mental well-being, it is necessary in order to move through the grieving process. The results of the study on self-forgiveness showed that people who practiced healthy, effective coping strategies while the care receiver was still living demonstrated less difficulty with forgiving oneself. A supported relationship

was also discovered between religious/spiritual practices and self-forgiveness. When a debilitating disability robs a person of functioning and of life, relief is often experienced by the person's survivors. In cases of Alzheimer's disease and related dementia, cognitive and physical decline is usually painful for caregivers to observe. When intense suffering accompanies dying, survivors feel that death gives relief to the loved one. Thus, self-forgiveness and decreased grief are noted in cases of extreme suffering (Jacinto, 2008).

CHAPTER THREE

Discussion and Implications

Numerous studies have researched on the topic of caregiver burden, distress and depression, strain/gain, and grief, and all have come up with similar, but varying results. One thing is certain: Assuming the caregiving role for a person with a debilitating, progressive disease such as Alzheimer's negatively affects a person's psychological well-being. When a disease as horrendous as Alzheimer's is acquired, reactions and coping techniques will vary across the board. Intense feelings of depression to isolation to anger to self-pity may be experienced, and they are all warranted. No study on interventions to reduce caregiver burden has concluded that counseling, education, and support groups are of no benefit. Therefore, small steps can be taken when a diagnosis is received to ensure mental health for the individual and the caregiver through the duration of the disease.

With more awareness about the disease of Alzheimer's and all of its implications, both those who are affected by the disease as well as those who are caregivers can more effectively cope with the situation. If those with Alzheimer's utilize the resources that are offered in the form of support groups, clinical studies, medications, and lifestyle changes, they could improve their quality and clarity of life, often simultaneously improving the quality of life of the caregiver. Unfortunately, no cure or proven treatment has been found to effectively slow, reverse, or stop the effects of Alzheimer's; but with more awareness about the disease comes more resources, thus bettering the chances of finding a more effective treatment. It is important for people to remember that Alzheimer's and other types of dementia are not just an "old age disease" and that it is never too soon to begin taking preventative measures in order to keep one's body healthy.

By the same token, the progressive stages of Alzheimer's disease will also greatly affect the lives of the caregivers. The research that shows the similar stages of distress and depression for both the caregivers and the care receivers also suggests promising results if both parties commit to health-promoting physical and psychological behaviors. As grave as the future can be for those battling Alzheimer's, they can experience peace about the diagnosis and development with appropriate coping techniques.

Better mental and physical health results in better quality of care to the person with the disability, thus resulting in better mental and physical health for the care receiver. In turn, when the care receiver experiences better health and less debilitation from a progressive disease, the caregiver feels less strain from a grim situation, and so on. A disease like Alzheimer's disease and other related dementias have a tendency to carry a stigma and sense of shame, capable of causing the decline of every facet of a human life and robbing the past, present, and future from the people that it consumes. Progressive and fatal diseases are always extremely difficult for everyone involved, but getting involved in interventions and treatments when the disease is diagnosed will assist in making easier adjustments. Therefore, maintenance of healthy well-being for the care receiver and caregiver is imperative to experiencing one's end of life in the most lucid, dignified manner possible. Taking part in education, counseling, clinical trials, peer support groups, effective coping techniques are proven methods of helping caregivers and receivers make smooth transitions throughout the stages of Alzheimer's disease.

Several limitations to serving those with Alzheimer's and their caregivers rear their ugly heads, especially when one searches for available facilities that specialize in Alzheimer's treatment using supplementary counseling in conjunction with medication

and well as in counseling the caregivers. To compound the problem, when and if support networks do exist, too often they are understaffed or unavailable in certain areas, such as in rural areas. Because rural areas are under-resourced whether by lack of education in the need for services or because of lack of state funding (which, by all appearances will worsen), those seeking support networking must choose between doing without or spending a small fortune in transportation and lodging in order to access services that exist in urban areas. In addition, while most researchers state that “further research of early psychosocial interventions including both the [individual with Alzheimer’s] and the caregivers” (Sorensen et al.) is important, research for this aspect of counseling takes time and money as does anything of value that benefits a specific group awaiting answers for cause and cure.

As aforementioned, too often medical doctors treat just the physical aspect of the disease without having learned and appreciated the worth of psychosocial interventions for both the individual and the caregiver. Within the DAISY study, researchers found that both the caregivers and the care receivers benefitted from and “highly appreciated the value of support groups and of being with peers” (Sorensen et al.). In a ten-day training program developed by the Austrian Alzheimerhilfe, persons with Alzheimer’s received stage-specific treatment in the form of cognitive and memory training, occupational therapy, and physiotherapy in addition to necessary medical treatment while their caregivers received counseling interventions separately. Results showed a marked effectiveness on key outcome measures for both parties (Stefanie, 2009). The overwhelming vote from researchers seems to be that pharmacotherapy and cognitive stimulation for the individual with Alzheimer’s represent good practice in conjunction

with offering the caregiver psychosocial intervention in managing stressors and strains (Brodaty, 2010). Unfortunately, while this writer has found that several source materials share this opinion, the current practice seems to cling to treating the physical aspect of the disease and “passing the buck” for funding and research.

The dilemma presented by under-resourced areas of the country, namely rural areas, circumvents several key issues. When the person with Alzheimer’s receives the diagnosis, life for everyone in the family is affected to some degree. Because research has shown that various people are affected in different ways, the coping strategies must be specific to those groups, such as ethnicity, gender, age, relation to the individual, among others. In the event that a rural area has both a medical facility and a mental health facility, often the healthcare professionals have received limited education outside of their areas of expertise. Doctors, for instance, may have received little to no education for mental health provision while therapists /counselors may have limited understanding of medical aspects, a sure downfall when these two professions should be able to work together for the good of the care receivers. In addition, when demand for specific intervention services is high, the supply may leave much to be desired, especially when limited staff/healthcare professionals are forced by circumstances sometimes unethically, to conduct services outside their own areas of certification and licensing (Smith, 2003).

Those individuals seeking support networking in rural areas may also meet the obstacle of cultural barriers within the rural setting (Berger, 2011). Often the people with Alzheimer’s and their caregivers refuse to seek help simply because of the stigma of the “small town talk,” especially in the arena of the rumor mill in which people who are totally uneducated in the aspects of the disease exacerbate the situation. In addition, a

certain sense of pride and “rugged individualism” still prevails among many older people who consider receiving help a sign of charity, even when services require payment. Individuals and their caregivers who live “out in the boondocks” are then forced to handle the situation themselves, becoming more isolated from an otherwise available system of support. In this event, phone counseling or “telemedicine” (Barton, 2008) can be a lifesaver when any other counseling is not an option for one reason or another.

Another pressing dilemma for caregivers and care receivers is the cost of transportation to faraway facilities, simply as an isolated cost of treatment. The total financial cost of the effects of Alzheimer’s is difficult to gauge because so many variables contribute to the estimation. Because a diagnosis may initially be indefinite, many will search the gamut of services that exist; and, then, paying for these services presents a huge and often overwhelming array of options. Although receiving care in the home may not necessarily ease the financial burden, people in the early stages of the disease typically still live at home, receiving care from family members and/or friends, the scenario for approximately seventy percent of Alzheimer’s cases. In 2008, over 10 million caregivers in the U.S. alone provided 8.5 billion hours of unpaid care, equal to an amount of \$94 billion. Still, while many helpful services exist for people with dementia, including home healthcare, adult daycare, residential care, and skilled nursing facilities do exist, these services become very costly (King & Podgorski, 2009), especially when transportation and the need for lodging are figured into the equation.

Though studies on the medical cure for Alzheimer’s continue to be conducted, few exist covering the benefit of intensive counseling throughout the stages of the debilitating disease. Obviously, counseling will not reverse or cure the disease, but it

may help the end years of one's life to be healthier and more lucid, thus allowing for more life satisfaction and closure. As aforementioned, treatment of such a serious disease requires a team of professionals, who sometimes lack the knowledge to collaborate effectively. Therefore, training medical doctors on the importance of counseling and training counselors on the medical aspects of the disease would allow each healthcare worker to appreciate and understand the different aspects that must be addressed. A great importance also lies in finding ways to make community resources for this population more readily available. Alzheimer's does not choose its people; it affects those from all races, classes, and geographic areas, which, unfortunately, leaves some with few to no options for vital resources. For that reason, measures should be taken to determine how to make outreach programs available across the board, without raising cost for those in rural areas.

Those who have no hope, essentially have hardly any reason to try. It is imperative that the implemented treatments can provide a sense of hope and safety for everyone involved. While medication can improve one's health, counseling can provide useful tools in controlling feelings, emotions, and the outlook of a situation, thus creating a sense of hope and facilitating effective conditions for recovery and lucidity.

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