The physical, psychological, and social impact placed on caregivers of people with Alzheimer's disease: a literature review

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Introduction

It has been projected that the proportion of the population who are older than 65 years of age will increase dramatically over the next 25 years and this increase will most likely result with more diagnoses of Alzheimer’s disease (Mausbach et al., 2007). Alzheimer’s disease is a growing problem in the United States with greater than 4 million Americans currently affected. These numbers are expected to increase to more than 8 million in the next 20 years (Thompson et al., 2004). Due to the financial burden of long-term care, many patients with Alzheimer’s disease are cared for at home by family members with approximately 70-80% of Alzheimer’s patients living at home (Thompson et al., 2004).

Although spouses, particularly wives, have been shown to be the main caregiver for people with Alzheimer’s disease, the number of husbands and adult children that care for their loved ones with Alzheimer’s disease is increasing. The stress and burden that often accompanies the caregiver-care recipient relationship pertaining to Alzheimer’s disease is often overwhelming and a decline in both the psychological and physical health of the caregiver may occur. In fact, one study concluded that there is a surplus of negative consequences that is associated with the caregiver experience including a lower quality of life, higher levels of depression and sense of burden, lower family satisfaction, increased levels of anger and hostility and a weaker immune system and compromised physical health (Thompson et al., 2004). Along with these negative consequences, caregivers are also conflicted emotionally, socially, and financially (Thompson et al., 2004). A recent study concluded that the distress expressed by caregivers of people with Alzheimer’s disease has been linked with both psychological and physical morbidity, including a greater risk for depressive symptoms, reduced well-being, poorer self-rated health, and even higher mortality rates when compared with non-caregivers (Mausbach et al., 2007).
These implications have an enormous impact on our society as well as the quality of life for both the caregiver and the care-recipient. Added to this already bleak picture is the fact that many caregivers reach the point in which they can no longer handle such a burdensome task of caring for their loved one with Alzheimer’s disease, which leads to long-term care placement and a dramatic increase in health-care costs and economic problems (Vellone et al., 2007). The economical burden that Alzheimer’s disease places on society is estimated to cost more than $1,000 billion. This doesn’t include the $43,000 per year that the family contributes towards caring for the individual with Alzheimer’s disease, which now makes Alzheimer’s disease the third costliest chronic disease to treat (Rice et al., 2001; MetLife Mature Market Institute, 2006).

Health care providers need to become more educated and aware of the consequences that accompany the experience of caring for a patient with Alzheimer’s disease, as well as recognizing that caregiving for Alzheimer’s disease is a different experience than caring for someone with a physical ailment. This would then lead to the development of interventions and support networks that could be implemented in order to assist in making the caregiving experience less burdensome. As a result, the health and quality of life of both the caregiver and the care-recipient can be enhanced. Caregivers of individuals with Alzheimer’s disease commit long hours of care to the care-recipient and, as a result, often suffer from their own individual physical, psychological, financial, and social demise. By being more aware of the increased health risks associated with caregiving, health care providers can provide more support and interventions for their patients that are caregivers and ensure that their health needs are being met. If caregivers remain healthy and well, they are more likely to continue caring for their family member with Alzheimer’s disease at home and they are less likely to become
overburdened. This can lead to less long-term care placement, which will cut down on medical costs dramatically.

The purpose of this literature review is to evaluate the effects of caring for a person with Alzheimer’s disease on the caregiver and to assess these outcomes based on the caregiver-care recipient relationship. For example, are there differences in outcomes if the caregiver is a male spousal caregiver versus a female spousal caregiver versus an adult-child caregiver? It is also important to incorporate how the different dynamics of Alzheimer’s disease affect the individual with Alzheimer’s disease, including cognitive disturbances, memory loss, behavioral/psychological changes, and personality changes, and how this relates to caregiver burden. It is also important to observe the physical, psychological, and social effects of the caregiver after long-term placement of the person with Alzheimer’s disease and the factors that led to institutionalization. Although the majority of studies focus on the negative outcomes of caring for an individual with Alzheimer’s disease, it is essential to also point out some of the positive outcomes of caring for an individual with Alzheimer’s disease, as well as focus on what the physician assistant can do in order to enhance the caregiver-care recipient relationship.

The following literature review will begin with an overview of Alzheimer’s disease and the clinical manifestations observed in individuals with the disease. A discussion of the general role of the caregiver as well as the basic demographical information of the caregivers and care recipients will follow. At the core of the paper, the physical and psychological implications that develop from caring for an individual with Alzheimer’s disease will be explored with an emphasis on how kinship and gender can play a role in caregiver burden. Other issues such as institutionalization and issues that make caring for an individual with Alzheimer’s disease different from caring for an individual with other disabilities or chronic illnesses are also
discussed. In the concluding section, the role of the physician assistant in the dynamic caregiver-care recipient relationship is explored and suggestions on how healthcare workers, specifically physician assistants, can enhance the quality of care for both caregivers and individuals with Alzheimer’s disease are provided.
Methodology

In order to accrue information for the literature review, a PubMed search using the following terminology was performed: Alzheimer's disease patients, spousal caregiver, adult-children caregiver, caregiver, health consequences, psychological consequences, grief of caregivers, effects of long-term placement, and caregivers of non-dementia patients. The search involved only caregivers that are caring for individuals with Alzheimer’s disease in the home and caregivers that were not suffering any major adverse health problems prior to taking on the role of caregiver. After reading through the various articles obtained from PubMed, the bibliographies of the articles collected were also thoroughly reviewed in order to ensure that all current research that is relevant to the topic of interest was obtained.
Literature Review

Individuals with Alzheimer’s disease can often live many years before the disease or another concurrent illness takes their lives. As mentioned previously, these patients are often cared for at home within the community by family members. Caregivers can be of any age and gender and often contribute a lot of time and effort in caring for their family memeber with Alzheimer’s disease. As a result, a physical and psychological deterioration in the health of caregivers is often a negative consequence of the caregiver-care recipient relationship. In fact, one study found that caregivers make 50% more physician visits and take over 85% more prescribed pharmaceuticals than their non-caregiving counterparts (Chumbler et al., 2003). Caregiver burden also inadvertently affects the person with Alzheimer’s disease in that the more burdened the caregiver feels, the more likely the caregiver is to resort to long-term care placement of their family member with Alzheimer’s disease (Vellone et al., 2007). This dynamic relationship is a complex obstacle that needs to be recognized by healthcare providers. In order to become more educated in this area, we need to first understand Alzheimer’s disease and the caregiver role as well as the psychological/emotional, physical, and social/financial implications that many caregivers face.
Alzheimer’s Disease

Alzheimer’s disease is the most common form of dementia among the elderly and affects more than 4 million Americans, with over 2 million spouses, relatives, and friends caring for these patients (Larson et al., 2004). Alzheimer’s disease is a progressive neurologic disorder that results in memory loss, personality changes, global cognitive dysfunction, and functional impairments (Soto et al., 2008). A number of behavioral and neuropsychiatric disturbances often accompany this disease (Cummings, 2004). Dementia resulting from Alzheimer’s disease is characterized by a decline primarily in the cortical aspects of cognition (e.g., memory, language, praxis) and follows a characteristic time course of gradual onset and progression (Lyketsos et al., 2006). Alzheimer’s disease is the most common form of dementia affecting older adults and accounts for 60 to 70 percent of progressive cognitive decline in the elderly population (Cummings & Cole, 2002).

Although Alzheimer’s disease cannot be definitively diagnosed without a brain biopsy, there are pathological and clinical characteristics that are common which ultimately leads to a clinical diagnosis. Alzheimer’s disease affects a global spectrum of the brain; marked atrophy as well as ventricular dilatation are observed in brain imaging procedures. Microscopically, there is a significant loss and shrinkage of neurons and many investigators believe that the vital pathological component of Alzheimer’s disease is the shrinkage of the dendritic apparatus of large neurons that leads to the loss of synapses (Yaari & Corey-Bloom, 2007). The neuropathologic hallmarks of Alzheimer’s disease are neuritic plaques and neurofibrillary tangles which are concentrated in vulnerable neural systems (Yaari & Corey-Bloom, 2007). However, these characteristics can be seen in normal aging individuals as well as other neurodegenerative diseases which is why it is vital to rule out other causes of dementia before
diagnosing an individual with Alzheimer’s disease. Other pathological characteristics often observed in the brains affected by Alzheimer’s disease are still under extensive research and include neuropil threads, granulovacuolar degeneration, and amyloid angiopathy (Yaari & Corey-Bloom, 2007). Amyloid angiopathy are vascular lesions that can be found in the small and medium cortical vessels of many Alzheimer’s disease brains, which is why many individuals with Alzheimer’s disease can portray a mixed dementia combination of dementia of Alzheimer’s disease and vascular dementia. Along with the neuropathological changes of the brain of Alzheimer’s disease, there are also neurochemical deficiencies as well with the most significant being decreasing cholinergic activity (Yaari & Corey-Bloom, 2007). Other neurochemical deficiencies of less severity include glutamate, norepinephrine, serotonin, somatostatin, and cortico-trophin-releasing factors (Yaari & Corey-Bloom, 2007; Cummings & Cole, 2002).

The diagnosis of Alzheimer’s disease requires a complete physical exam and medical history as well as brain imaging and lab tests. There are currently two similar criteria systems utilized to establish a clinical diagnosis of Alzheimer disease. They include the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) and the National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer’s Disease and Related Disorders Association (NINCDS-ADRDA) criteria (Yaari & Corey-Bloom, 2007). The criteria are very similar and include a gradual progressive dementia of adult-onset that inhibits the individual’s ability to engage in social or occupational activities. Dementia requires a decline in memory as well as one other cognitive symptom such as visuospatial skills, language and calculation, praxis, gnosis, or frontal or executive dysfunction (Turner, 2006). It is important to exclude other etiologies as a possible cause of the dementia. Unfortunately, in order to make a definitive diagnosis of Alzheimer’s disease, a brain biopsy or necropsy must be performed.
However, this is seldom done and most diagnoses of Alzheimer’s disease are probable (Turner, 2006). The most significant risk factor for developing Alzheimer’s disease is age (Yaari & Corey-Bloom, 2007). This is not to suggest that Alzheimer’s disease is a natural process of aging; however, it is clear that the prevalence of Alzheimer’s disease increases after the age of 65 and doubles approximately every 5 years between the ages of 65 and 95 (Yaari & Corey-Bloom, 2007). Genetics is another important risk factor for acquiring Alzheimer’s disease. Having a first-degree relative with Alzheimer’s disease increases one’s risk two-to-fourfold (Turner, 2006). Other possible risk factors include female gender, lower education levels, and head trauma (Yaari & Corey-Bloom). It has also been postulated that Down’s syndrome and stroke risk factors such, as hypertension, diabetes mellitus, smoking, and hypercholesterolemia, make an individual more susceptible to developing dementia of Alzheimer’s disease (Turner, 2006).

It is difficult to isolate the exact onset of Alzheimer’s disease because the disease is a gradual, progressive decline in the cognition of the individual affected. The early phases of the disease most often attacks short-term memory first. Difficulty in recalling new information and disorientation to time and place are common concerns that the family and individual with Alzheimer’s disease present with at the initial visit with the primary care provider. Remote memory is usually preserved until the late stages of the disease (Yaari & Corey-Bloom, 2007). As the individual with Alzheimer’s disease progressively declines into the intermediate stage of the disease, difficulties with language advance. The intermediate stage is characterized by deterioration of logical reasoning, planning, and organizing, decline of remote memory, deterioration in language, deterioration in concentration, loss of insight into disease, loss of skills
such as dressing and using appliances, deterioration of spatial orientation, and loss of emotional control. One of the most difficult issues that develop in individuals with Alzheimer’s disease is sleep disturbances. Wandering at night becomes a critical concern for caregivers (Yaari & Corey-Bloom, 2007).

Alzheimer’s disease gradually affects the patient’s activities of daily living (ADL) to the point that the patient requires full-time care and assistance in all ADL and instrumental activities of daily living (IADL). Behavioral and psychological tribulations, often referred to as neuropsychiatric symptoms in the literature, are quite common and often times can precede the cognitive dysfunction. Initial symptoms can include confusion, urgent need to toilet, anger, failure to remember words, unpredictable or inappropriate responses, and momentary agitation (Hubbell & Hubbell, 2002). Other neuropsychiatric symptoms include aggression/agitation, apathy, anxiety, depressive symptoms, and delusions (Zuidema et al., 2007). Hallucinations and delusions, which are experienced by many individuals with Alzheimer’s disease, exacerbate the behavioral problems even more. These neuropsychiatric symptoms are highly prevalent at all stages of Alzheimer’s disease. It is estimated that between 60 and 80 percent of individuals with Alzheimer’s disease will experience neuropsychiatric symptoms at some point during the disease progression (Zuidema et al., 2007). Due to the fact that these symptoms are both common and difficult to treat, focused care pertaining to these issues is vital when treating an individual with Alzheimer’s disease.

The care that individuals with Alzheimer’s disease require leads to significant direct costs, such as healthcare services, hospital care, and nursing home care, as well as a plethora of indirect costs such as unpaid caregiver services and reduced caregiver productivity. These additional expenses impose a tremendous burden on the patient, the caregiver, and society as a
whole (Burns & Rabins, 2000). It has been estimated that the annual cost to the United States economy is $60 billion (Cummings et al., 2002). This further supports the need for health care providers to be in tune with both the caregiver and the individual with Alzheimer’s disease in order to fully understand the current medical conditions of the patient.

The prognosis for Alzheimer’s disease is grim and, as of now, there is neither a cure nor a therapeutic remedy to halt the progression of the disease. Although the progression of the disease can vary, the usual progressive decline continues on an average of 8 to 12 years. It eventually leads to severe deterioration of all cognitive abilities and ends in a vegetative state and death (Turner, 2006). It is hopeful that future progressions in the treatment of Alzheimer’s disease can somehow find the missing piece that has yet to be discovered. In order to begin to understand the changes that need to be implemented, it is imperative to study the dynamic relationship between the caregiver and the individual with Alzheimer’s disease because this is the foundation for the continuity of caring for these individuals in the familiarity of their own homes. In the following section, the caregiver role will be broken down in order to gain better understanding into the caregiver-care recipient dyad.
Caregiver Role

The National Alliance for Caregivers estimates that there are over 44 million caregivers age 18 and older in the United States, representing 21 percent of all U.S. households (McCurry et al., 2007). Of these caregivers, roughly 10 million are informal, non-paid caregivers for individuals with Alzheimer’s disease (Alzheimer’s Association, 2008). In 2007, caregivers for individuals with Alzheimer’s disease dedicated 8.4 billion hours of unpaid care, a contribution to the nation valued at $89 billion (Alzheimer’s Association, 2008). Families and primary caregivers for family members with Alzheimer’s disease are at a great risk of putting their own health, both physically and psychologically, at risk. These problems can be related to an increased risk of burden and mortality (Andren & Elmstahl, 2008).

Demographics

The typical profile of a caregiver for an individual with Alzheimer’s disease is a 48 year old married woman who is employed (Alzheimer’s Association & National Alliance for Caregiving, 2004). Most primary caregivers of individuals with Alzheimer’s disease are relatives (87 percent), with adult children caregivers being the most common (Alzheimer’s Association & National Alliance for Caregiving, 2004). Both the young and the old take on the duty of caring for a family member with Alzheimer’s disease. Among caregivers age 18 years and older, 19 percent were under age 35, 29 percent were between the ages of 35-49, 37 percent were between the ages of 50-64, and 14 percent were age 65 years and over (Alzheimer’s Association & National Alliance for Caregiving, 2004). The typical Alzheimer’s care recipient is a 78 year old widowed woman. Thirty-five percent of Alzheimer’s recipients are 85 years old or older (Alzheimer’s Association & National Alliance for Caregiving, 2004).
Half of these caregivers are primary caregivers, with 30 percent providing all of the unpaid care and 23 percent providing most of the care (Alzheimer’s Association & National Alliance for Caregiving, 2004). Added on to this already rigorous commitment, 57 percent of Alzheimer’s caregivers work full or part time, with 66 percent missing work because of their caregiving responsibilities (Alzheimer’s Association & National Alliance for Caregiving, 2004). Most caregivers live with the person with Alzheimer’s disease and those that don’t, visit the person daily in order to assist in daily living. Although many caregivers voluntarily take on this job of caring for their loved one, there is a certain amount of burden that can be associated with such a demanding task.

**Caregiver Burden**

Caregiver burden has been defined as the physical, psychological, emotional, social, and financial problems that can be experienced by family members caring for impaired older adults (McCurry et al., 2007; Andren & Elmstahl, 2008; Vellone et al., 2007). Caregiver burden can be divided into an objective component and a subjective component. Objective burden deals with the events that are associated with a negative experience of caregiving as well as the consequences of both behavioral and physical changes of the individual with Alzheimer’s disease. The subjective component deals with emotional and psychological consequences that the caregiver experiences, such as anxiety and depression (Mahoney et al., 2005).

On a daily basis, caregivers experience a sense of grief that can be differentiated from depression. Grief occurs when the safety and security that a person feels within a relationship becomes threatened (Ott, Sanders & Kelber, 2007). Caregivers often feel a sense of loss in their previous role in the relationship at the same time that they are taking on the new role as a caregiver.
The amount of stress a caregiver experiences is also related to certain situations and different kinships to the individual with Alzheimer’s disease. For example, older spousal caregivers may experience stress due to physical and financial stressors while adult children caregivers may have conflicting responsibilities such as work or children (Oyebode, 2003; Pinquart & Sorensen, 2003). As the disease progresses, the individual becomes more dependent on the caregiver, which only results in more hours spent caring for the individual. It has been found that caregivers can spend up to 70 hours a week caring for their family member with Alzheimer’s disease (Martin-Carrasco et al., 2008).

Unlike the progressive decline of the cognitive symptoms of Alzheimer’s disease, the behavioral and psychological symptoms of Alzheimer’s disease are often very unpredictable, which can lead to a high amount of stress in the caregivers. It is vital to both our society and the health care arena to recognize the consequences of the burdens placed on caregivers of individuals with Alzheimer’s disease due to the fact that the mental and emotional strain experienced by these individuals has been shown to be an independent risk factor for increased mortality (Schultz & Beach, 1999).

It has also been postulated that the behavioral disturbances is one of the most significant factors contributing to caregiver burden (Beeri et al., 2002). Behaviors such as aggression and nighttime wandering significantly affected caregiver burden and it was often these factors that led to nursing home placement due to burden overload experienced by the caregiver (Gaugler et al., 2005). This suggests that caregivers handle the physical and cognitive deficits better than the behavioral problems of the care recipient (Pinquart & Sorensen, 2003).

It is important to consider the role in which caregiver characteristics has on the decline of neuropsychiatric symptoms of the individual with Alzheimer’s disease. One idea that has been
developed in studies pertains to the expression of neuropsychiatric symptoms as a result of unmet needs of the individual with Alzheimer’s disease. This concept would lead us to conclude that the dynamic caregiver-care recipient relationship could contribute to the development and expression of these neuropsychiatric symptoms in individuals with Alzheimer’s disease (Sink et al., 2006). This is imperative in providing anticipatory guidance for the caregiver in regards to dealing with many of the psychological and behavioral problems associated with Alzheimer’s disease. It is possible to prolong the development of these symptoms by inhibiting events that exacerbate them. It would then be necessary to observe caregiver characteristics and the contribution that these have in the occurrence of neuropsychological symptoms in individuals with Alzheimer’s disease.

*Psychological Consequences*

Numerous studies have observed the psychological consequences that the caregiver experiences as a result of caring for an individual with Alzheimer’s disease. A recent study done by Mahoney et al. (2005) was interested in discovering what makes certain caregivers more susceptible to developing anxiety and depression. Interviews were conducted on 153 caregivers for individuals with Alzheimer’s disease. Demographic information pertaining to age, gender, relationship to care-recipient, employment status, and marital status, as well as care-recipient age and gender, were collected. Based on the interviews, a scale was used in order to assess anxiety and depressive symptoms among the caregivers. Concluding results showed that roughly a quarter of the caregivers were shown to be affected by anxiety and ten percent of these individuals were depressed. It was the detriment of the ADL as opposed to the cognitive decline that was a greater predictor for caregiver anxiety. Overall, both the physical health of the caregiver and the depth of the relationship between caregiver and care-recipient influenced the
development of anxiety and depression in the caregivers. However, increased depressive symptoms in the care-recipients with Alzheimer’s disease had a direct affect on the psychological morbidity of the caregiver. This emphasizes the interdependency that develops between the caregiver and care-recipient experience as their relationship evolves with the progression of the disease. One disadvantage in this study was that past psychological medical issues as well as past-usage of psychotropic drugs were not explored, which could have changed the results of the study if this were accounted for.

When the psychological state of the caregiver declined, his/her physical health was also affected. Increased depressive symptoms and adverse reactions to care-recipient behaviors were found to be significant predictors of the caregiver’s risk of developing cardiovascular disease within eighteen months of caring for his/her loved one (Mausbach et al., 2007).

Impairment in ADL in the care-recipients as opposed to cognitive impairment was also found to be related to an increase in caregiver anxiety. This suggests that it is the additional burden of physical impairment as opposed to the progressive decline in cognitive abilities that are more burdensome to the caregiver. This can increase the risk for both physical and psychological problems in the caregiver (Mahoney et al., 2005). In addition, aversive feeding behaviors in individuals with Alzheimer’s disease resulted in a higher level of burden in the caregiver, which correlates with other findings that concluded that there is a strong association between the level of caregiver burden and assistance with ADL and IADL (Riviere et al., 2002). Considering that caregiver burden is directly related to the amount of time caregivers spend per week caring for the individual with Alzheimer’s disease as well as the number and type of activities performed for the care recipient, it is vital to educate these caregivers on behavior...
modification strategies in order to minimize time spent on ADL (Alzheimer’s Association & National Alliance for Caregiving, 2004).

**Positive Outcomes of Caregiving**

Although the majority of research pertaining to caregivers of individuals with Alzheimer’s disease focuses on the negative health consequences of the caregiver experience, there are many rewards that can come out of caring for a loved one diagnosed with Alzheimer’s disease. Caring for a loved one with Alzheimer’s disease has been described as a constant emotional roller-coaster of feelings such as stress, frustration, and the never-ending day-to-day care, along with managing difficult symptoms, protecting their loved one from harm and embarrassment, and dealing with the progressive memory loss. However, regardless of the losses and frustrations that a diagnosis of Alzheimer’s disease often brings, the majority of caregivers (78 percent) found positive aspects that came from caring for their loved one with Alzheimer's disease such as cherishing the time spent with each other and creating memories through various activities (Butcher et al., 2001).

Caring for a loved one with Alzheimer’s disease requires long hours of work and stressful situations. However, the experience can also lead to positive emotions such as feeling useful and having an improved self-esteem due to the perception of being able to handle difficult situations and being able to take care of their loved one (Mannion, 2008). Caregivers often report that the experience of caring for an individual with Alzheimer’s disease has changed their lives in a more positive and meaningful way, which has enabled them to offer support for others going through the same experience as well as becoming life-long advocates for more effective interventions (Karlin, 2001). Keying in on coping methods and support within the community is an important
aspect in finding ways for caregivers to have a meaningful caregiving experience, as well as preserving the relationship between the caregiver and their loved one with Alzheimer’s disease.

Many of the studies that have focused on the positive outcomes of caregiving have found a direct correlation between race and the rewards and benefits of caregiving. Studies of African American and Caucasian caregivers have reported that African Americans caregivers continuously found more gains than the Caucasian caregivers in regards to their caregiving experience (Janevic & Connell, 2001; Rapp & Chao, 2000). When observing Caucasian caregivers, it was found that those who had a traditional ideology of care, such as “taking care of one’s own,” had more satisfaction and positive outcomes from the caregiving experience (Foley et al., 2002). Interestingly, African American and Hispanic families approach the caregiving task as a unit and responsibilities are divided among different individuals of the family, which is in stark contrast to the “one primary caregiver” role that most Caucasians adopt (Cummings et al., 2002). According to the study done by Roff et al., (2004) African American caregivers of individuals with Alzheimer’s disease experienced more satisfaction and positive outcomes in their caregiving experience due to the significant role that their religion has on their perspective on challenging issues. More research is needed at this time in the area of how race and religion can have a positive impact on the dynamic caregiver-care recipient relationship.

Older caregivers were often found to report a more rewarding experience as a caregiver than their younger counterparts (Picot et al., 1997). Other factors that have been shown to have an affect on the caregiver experience include socioeconomic status and the degree of anxiety from the care recipient’s behavior. Individuals with Alzheimer’s disease who are cared for by older spousal caregivers were shown to have less agitation and wandering. Older spousal caregivers are often more aware of their spouse’s pre-morbid personality and behavior and, as a
result, they are more efficient at modifying the environment and interactions in order to prevent behavioral disturbances (Sink et al., 2006).

The caregiving experience is both rewarding and challenging. The relationship that exists between the caregiver and the care-recipient is far from static. As the disease progresses, the caregiver as well as the care-recipient are both faced with a kaleidoscope of obstacles. It is only when we as a society become more aware of these obstacles as well as the pros and cons associated with caring for an individual with Alzheimer’s disease will we be able to develop a foundation for treating both caregiver and care-recipient. The following discussion will explore the different relationship that can exist between the caregiver and care-recipient in regards to Alzheimer’s disease.
The Spousal Caregiver-Care Recipient Relationship

Spouses are common caregivers for individuals with Alzheimer’s disease and wives are more likely to act as the primary caregiver (Allen et al., 1999). Spousal caregivers comprise roughly 23 percent of all caregivers for family members with Alzheimer’s disease (Oyebode, 2003). Husbands and wives react differently to the various situations that may arise from this complicated disease and more often than not, wives are more negatively affected in regards to their quality of life (Yee & Schulz, 2000; Almberg et al., 2000). The emotional instability of the individual with Alzheimer’s disease was found to be the strongest predictor of impaired quality of life in the caregiver, with caregivers that were wives being more vulnerable than husband caregivers (Croog et al., 2001). It is important to observe the level of burden that is placed on spousal caregivers and how this affects their overall well-being.

Spousal Caregiver Burden

Spouses, who are usually older and closer to age with the care-recipient, appear to experience strain due to physical or financial problems (Oyebode, 2003). Spousal caregivers have more caregiver burden associated with physical impairments and behavioral problems of the individual with Alzheimer’s disease as well as a longer duration of care than other caregivers (Pinquart & Sorensen, 2003).

Spousal caregiver burden is exacerbated by feelings of inadequacy in caring for the spouse with Alzheimer’s disease. Anger and resentment are very common emotions that many of these caregivers express. Many of the spousal caregivers feel as if they are not doing enough for their spouse with Alzheimer’s disease and this ultimately leads to further anxiety and helplessness (Croog et al., 2004). The burden of caring for a spouse with Alzheimer’s disease can often be linked to such conditions as caregiver depression, anxiety, impaired quality of life,
elevated blood pressure, alcohol abuse, as well as a plethora of other physical and psychological problems (Croog et al., 2001).

Spouses who care for their significant other who has been diagnosed with Alzheimer’s disease experience a loss of the significant bond that exists in the marital relationship. The relational deprivation reported by spousal caregivers of people with Alzheimer’s disease have been found to be directly correlated to the decline of their mental health, such as depression, as well as their physical health (Beeson, 2003). Although the spouse with Alzheimer’s disease is still physically present, his/her personality progressively evolves into something different and the relationship he/she once had with the spousal caregiver no longer exists. The marital bond based on intimacy and emotional connections unravels into one without reciprocity from the spouse with Alzheimer’s disease (Croog et al., 2004). As the disease progresses and manipulates the identity of the affected spouse, the intimate and reciprocal marital relationship is replaced by the new evolving relationship of caregiver-care recipient. The caregiver’s spouse is still physically present; however, the emotional and psychological components of the relationship are gone (Beeson et al., 2003).

When observing spousal differences in regards to perceived caregiver burden, it has been observed that there is a direct association between gender and patient stressor burden. The well being of the spousal caregiver often deteriorates and many of these individuals experience both anxiety and depressive symptoms (Croog et al., 2001). One study concluded that female spousal caregivers were more likely to report a lack of well-being and a decrease in psychosocial health than husband spousal caregivers (Chi-Jun, 2005). Research has consistently shown that female spousal caregivers are more depressed and experience more episodes of loneliness than male spousal caregivers (Beeson et al., 2000).
Younger spousal caregivers are at a higher risk for developing negative health consequences due to the caregiver stressors than older spousal caregivers (Beeson et al, 2000). However, when considering the age component, younger male spousal caregivers were more similar to younger female spousal caregivers than their older male counterparts in regards to caregiver response to the burdens of caring for an individual with Alzheimer’s disease. This could possibly be explained by the older husband’s outlook on the physical health of his spouse in that most individual’s expectations of health diminish with age. The loss of health might be extremely devastating to a younger spouse whereas older spouses are more likely to accept the losses associated with Alzheimer’s disease as the “normal” process of aging. This supports the idea that as one ages, his/her perception on health and caregiver burden evolves into a stage of acceptance (Croog et al., 2001).

*Physical and Psychological Consequences of Caregiver Burden*

After accounting for age, length of time acting as primary caregiver, social support, and coping resources, differences were found in the way husbands and wives reacted to the stressors of the caregiving experience. A study conducted by Thompson et al. (2004) was interested in observing the differences between husbands and wives that were caregivers for their spouses with Alzheimer’s disease. The study cohort consisted of 45 female spousal caregivers and 16 male spousal caregivers from New Mexico and south Texas. The spouses ranged in age from 56 to 84 years of age and all caregivers resided with their spouse with Alzheimer’s disease. The caregivers were given a questionnaire pertaining to demographic information, perceived stress level, and caregiver burden. Blood was drawn in order to obtain a blood cell count and assess immunological response to stressors and bioinstrumentation was implemented in order to observe temperature and heart rate changes in response to stress and relaxation. Results from this
study concluded that there were significant differences in the ways in which female spousal caregivers and male spousal caregivers react to the caregiving experience. The female spousal caregivers reported a more negative emotional response towards caring for their spouse with Alzheimer’s disease. Emotions such as anxiety, depression, and stress were more prominent in the female spousal caregivers. Overall, the female spousal caregivers from this study reported a higher level of burden than the male spousal caregivers. Thompson et al. (2004) pointed out that it could be the differences in the ways in which male spousal caregivers perceive caregiver burden that accounts for the sex differences in responses to the stressors of caring for an individual with Alzheimer’s disease. The ability of the male spousal caregivers to resist becoming stressed by the caregiver experience could be explained by their ability to view life as, “ordered, predictable, and manageable.” It seems that the male spousal caregivers viewed the caregiving experience from a more objective perspective whereas the female spousal caregivers were more subjective in their perceptions. The findings from this study are significant because it is a known fact that one’s level of stress can greatly impact both his/her physical and psychological well-being. It is important to identify vulnerable individuals at risk for chronic stress in order to implement interventions that can alleviate some of the stressors associated with caring for a spouse with Alzheimer’s disease.

Another recent study that was conducted by Mannion (2008) was interested in studying the affects that caring for a spouse with Alzheimer’s disease has on the caregiver’s psychological and physical health. A self-administered survey was given to 100 spousal caregivers who were registered with the Alzheimer Society of Ireland, Galway, or Mayo. Only 44 questionnaires were returned, however, one was deemed incomplete due to the death of the spouse, giving the study 43 subjects. The spouses ranged in age from 49 to 63 years old. There were 34 female spousal
caregivers and 9 male spousal caregivers. The results from this study showed that 40 percent of the spousal caregivers subjectively reported their health as fair or poor. One major point that this study supported was that gender had a huge impact on how one was affected, both physically and psychologically, by the caregiving experience. In fact, this study concluded that seventy-five percent of the female spousal caregiver respondents reported poorer health compared to twenty-five percent of their male counterparts (Mannion, 2008). Another significant finding was that 78.8 percent of the female spousal caregivers reported depressive symptoms as opposed to 33.3 percent of the male spousal caregivers. However, it is important to keep in mind that females comprise the majority of caregivers. Due to this, most studies that investigate spousal caregivers for individuals with Alzheimer’s disease have very few male spousal caregiver subjects, which could greatly impact the study’s results. More research involving a larger study population is needed in order to develop generalized conclusions regarding the health of spousal caregivers for individuals with Alzheimer’s disease.

It is clear from previous research that spousal caregivers are affected by caregiving experience, both emotionally and physically. Based on subjective measures, female spousal caregivers perceived a higher level of stress, including depression and anxiety, than husbands that were caregivers (Yee & Schultz, 2000; Thompson et al., 2004; Mannion, 2008). There has also been documented evidence that female spousal caregivers experience a greater decline in physical health than male spousal caregivers and this only worsened after placement of their loved one in a long-term facility (Leon et al., 2000; Lieberman & Fisher, 2001).

Differences in physiological outcomes between male spousal caregivers and female spousal caregivers have also been observed (Atienza et al., 2001). A recent study reported that female spousal caregivers who provide nine or more hours of direct care per day had an
increased risk of developing coronary artery disease (Lee at al., 2003). This could be explained by the hypercoagulable state that often develops in a state of chronic stress, leading to increased risk for hypertension and cardiovascular disease. The D-dimer level, which is a fibrin degradation fragment, is used quantitatively to assess conditions that cause hypercoagulability. Numerous factors such as stress, physical illness and sleep deprivation can all contribute to a hypercoagulable states which can greatly impact one’s risk for developing cardiovascular problems. However, a study conducted by Mills et al. (2008) concluded that male spousal caregivers had a 27 percent higher D-dimer level than female spousal caregivers of loved ones with Alzheimer’s disease, which could be a result of a lack of sleep. This resulted in male spousal caregivers having a greater risk for increased thrombosis and inflammation associated with cardiovascular disease. Although different studies have contradicting findings, it is clear that both female and male spousal caregivers are affected physiologically due to the increase in levels of stress from the caregiving experience.

Sleep disturbance is a significant problem for spousal caregivers of loved ones with Alzheimer’s disease, with two-thirds of spousal caregivers experiencing some kind of sleep disturbance (Creese et al., 2008; McCurry et al., 2007). In a recent study done by Creese et al. (2008), 63 percent of spousal caregivers admitted to some kind of sleep disturbance as a result of caring for their loved one with Alzheimer’s disease and over half of these individuals experienced these disturbances at least three times per week. Many caregivers deal with the chronic stress of caring for their spouse on a daily basis and have trouble relaxing and letting go of these stressors when going to bed. The degree of caregiver burden was a significant indicator of sleep disturbances of spousal caregivers and disturbances in one’s sleep can have detrimental health consequences for spousal caregivers (Creese et al., 2008). These sleep disturbances can be
a result of the increase in nocturnal awakenings and wandering of spouses with Alzheimer disease and is worse in couples that continue to share a bed throughout the disease progression (Creese et al., 2008). However, the negative consequence of sleeping in a different bed from the spouse affected by Alzheimer’s disease could lead to a greater sense of loss, which would be a reason the caregiver would continue to sleep in the same bed as his/her loved one. Male spousal caregivers for spouses with moderate to severe Alzheimer’s disease were awake 54 minutes longer during the night than female spousal caregivers caring for a spouse with Alzheimer’s disease (Mills et al., 2008). Sleep disturbance in spousal caregivers of loved ones with Alzheimer’s disease is directly associated with an increase in depressive symptoms as well as an increase in caregiver burden (Creese et al., 2008).

It also becomes important to observe the care-recipient gender in terms of caregiver burden. Some studies show that care-receiving husbands were less likely to exemplify behavioral symptoms, were less likely to wander, and were overall less cognitively impaired than care-receiving wives (Calasanti & King, 2007). Some scholars found that more stress and burden was experienced in caregivers of male individuals with Alzheimer’s disease, however, more studies are needed in this area in order to develop a concrete relationship between gender of the care-recipient and caregiver burden (Gonzalez-Salvador et al., 1999).

Female Spousal Caregivers

The differences in the health and psychological outcomes of female spousal versus male spousal caregivers that can occur due to caring for a loved one with Alzheimer’s disease could be explained by the fact they view the caregiving experience differently. Female spousal caregivers tend to become more intricately involved in the experience and personalize everything whereas male spousal caregivers view the caregiving experience as a task that needs to be
accomplished and take on a more managerial approach to the caregiving experience (Hagedoorn et al., 2002). Female spousal caregivers tend to have a much broader support network and a more emotionally-based coping style. They are also less likely to resort to depersonalization when under stress (Hubbell & Hubbell, 2002).

An interesting study conducted by Perry (2002) investigated female spousal caregivers and how they migrated through a process of interpretive caring as they adopted the role of caregiver to their husbands with Alzheimer’s disease. The subjects were recruited from support groups, day care centers, and a university-affiliated diagnostic and outreach clinic. Tape-recorded interviews were conducted on 20 female spousal caregivers who ranged in age from 57 to 82 years old. The focus of the interview was the daily interactions that took place between the spouses and how the female spousal caregivers had evolved into the role of caregiver for their husbands with Alzheimer’s disease. The foundation for analyzing the process of interpretive caring evolved around the idea that emotional, cognitive, and behavioral factors all play a part in the caregiver’s conceptualization of both their spouse with Alzheimer’s disease as well as the disease itself. It was found that wives tend to undergo a progressive process of internalizing their thoughts and feelings in order to deal with the experience of caring for their spouse with Alzheimer’s disease. They begin by exploring and sorting out their feelings towards their husband’s forgetful behavior. After realizing that their husbands were no longer adequately functioning, they took on the roles that their husbands previously had. As the disease progressively altered the identity of their husbands, wives adopted a new identity for their husbands that were now affected by Alzheimer’s disease. However, the wives still had a sense of being unified as a couple and having the presence of their husbands on a daily basis was enough to bring satisfaction to many of these female spousal caregivers, regardless of the fact that many
of these husbands had taken on a completely different personality. Female spousal caregivers often sacrificed their own life by giving up the activities that they once enjoyed as well as suppressing any negative emotions they were experiencing from a lack of social contact. They felt that by doing this, they could avoid any emotional or behavioral outbreaks that could exacerbate their husband’s already unstable condition.

When approaching difficult tasks that husbands with Alzheimer’s disease resist, such as bathing, the wife caregiver often used manipulation tactics, such as lying, in order to get her husband to be compliant. Husband caregivers, on the other hand, were more concerned with the task at hand as opposed to trying to please their wives and often relented to forced physical means, such as picking the care recipient up and holding her under the shower to bathe. Although this was often difficult for the husband caregivers, they realized that keeping their wives clean, healthy, and safe were top priority (Calasanti & King, 2007).

The distress that female spousal caregivers experience results in a disruption in the caregiver-care recipient relationship and this feeling of inadequacy tends to exacerbate the anxiety that is felt by many female spousal caregivers (Thompson et al., 2004). Female spousal caregivers were found to dedicate more hands-on, general care to their loved ones, such as shopping, dressing/bathing, cleaning/cooking, and transportation than their male counterparts (Rapp & Chao, 2000). In general, the differences in the way in which female and male spousal caregivers perceive and express caregiver burden can be explained by the different ways in which they manage the caregiving task. Women tend to take on a supernatural role in which they try and do everything for their loved one whereas men tend to break each task up and to conquer them one at a time (Clyburn et al., 2000).
Female spousal caregivers often struggle with how to help their husbands with Alzheimer’s disease keep their identity without experiencing the humiliation that can occur with awareness of incompetence. However, on a more positive note, after female spousal caregivers accepted the fact that their husbands were, in a sense, different people, they began to discover the increase in knowledge and skills that developed from caring for their husbands as well as a sense of satisfaction of being able to provide care and assistance to their loved ones (Perry, 2002). This goes to support the idea that caring for a loved one with Alzheimer’s disease isn’t completely filled with burden and frustration but that there can be some positive and gratifying outcomes to the caregiving experience (Butcher et al., 2001).

Women have always been viewed as the caregiver of the family unit and due to the increase in life expectancy as well as the surge of baby boomers, both women and men are now needed more than ever in the care of older adults. Due to this increasing demand, more and more males are now taking on the role as primary caregiver for their spouses.

Male Spousal Caregivers

Male spousal caregivers comprise over 36 percent of spousal caregivers for individuals with Alzheimer’s disease (Shanks-McElroy & Strobino, 2001). Many scholars believe that husband spousal caregivers are less likely to experience stress and depression due to increased burden of caring for their spouse with Alzheimer’s disease than wives that are caregivers (Yee & Shulz, 2000).

However, this is not the traditional role of most men, which would lead one to suspect that men and women would approach the caregiving situation quite differently (Calasanti & Bowen, 2006). Husband caregivers adopt a style based on exerting force, focusing on tasks,
blocking emotions, minimizing disruption, distracting attention, and self medicating (Calasanti & Bowen, 2006).

Male spousal caregivers experience both physical and psychological health problems as a result of caring for their wives with Alzheimer’s disease. The level of care required by the person with Alzheimer disease, the frequency of behavioral dysfunction, caregiver perceptions of stressfulness of behavioral dysfunction, and leisure satisfaction were all found to be significant risk factors for poorer physical and emotional health of husband spousal caregivers (Shanks-McElroy & Strobino, 2001). When observing the physical consequences, it has been suggested that male spousal caregivers experience more significant cardiovascular consequences as well as more adverse immunological changes as a result of caring for their loved one with Alzheimer’s disease and these adverse health complications were directly correlated with the severity of their wives’ behavioral dysfunction (Vitaliano et al., 2002; Shanks-McElroy & Strobino, 2001).

However, there are some studies that show that male spousal caregivers actually experience less stress related to the caregiving experience, which could be explained by the fact that men have a different perception on the caregiving experience as well as their measure of success (Thompson et al., 2004). They tackle the caregiving experience first by identifying the issue at hand followed by mastering their ability and skills to carry out this task. (Thompson, 2004; Calasanti & King, 2007). Husband spousal caregivers often don’t experience the same magnitude of stress as wives because they don’t view the challenges of caring for their wives as a direct reflection of their manhood (Calasanti & King, 2007).

Other literature suggests that male spousal caregivers could possibly experience more stressors than female spousal caregivers in regards to “caregiver burnout” (Hubbell & Hubbell, 2002). This contradicts the majority of research that states the female spousal caregivers are
more affected by caregiver burden. Male spousal caregivers are less likely to utilize outside
sources for assistance in caring for their wives with Alzheimer’s disease. Why this occurs is still
of question, however, some theories suggest that “societal norms” plays a significant role in
one’s perspective on caregiving roles. Society seems to view the role of caregiving as a female
role and when a male spouse takes on this task, it is more likely to be viewed as a burden.

The psychological state of spousal caregivers is greatly affected. A study done by Schulz
and Williamson (1991) revealed that female spousal caregivers had a more static level of
depression throughout the caregiving experience. However, male spousal caregivers experienced
significantly more depressive symptoms that occurred progressively over time. Husband spousal
caregivers often struggle with coping methods for the loss that both spouses were experiencing
as a result of Alzheimer’s disease. Husband caregivers often had more difficulties dealing with
depression when it did occur and relied on substance abuse, such as alcohol and medications, to
deal with these unwanted feelings (Calasanti & King, 2007). Interestingly, male spousal
caregivers were found to experience a greater degree of psychological distress when they had to
bathe or toilet their loved one because those are activities that they viewed as private and
personal (Shanks-McElroy & Strobino, 2001).

Male spousal caregivers were found to resist outside help from support groups, family, or
other organizations during the initial stages of caring for their loved one with Alzheimer’s
disease (Butcher et al., 2001). However, it was reported in another study that males used more
in-home services than females, although female spousal caregivers used more informal support
and transportation services (Sun et al., 2008). This could be due to the fact that women
traditionally performed at-home-tasks so they didn’t perceive this as an added burden whereas
some of the male spousal caregivers might have been forced to take on this extra duty due to his
wife’s illness. However, it is important to keep in mind that female spousal caregivers could be more comfortable reporting their reliance on outside informal assistance whereas male spousal caregivers could be more reluctant to admit to using outside resources for assistance. This could potential result in underreporting of male spousal caregiver’s use of community resources for caring for their wives with Alzheimer’s disease (Sun et al., 2008).

Male spousal caregivers were shown to have a high sense of coherence (SOC) which meant that they viewed the caregiver experience as more manageable and experienced less burnout (Thompson et al., 2004). The burden that male spousal caregivers did experience was most commonly related to social isolation as well as a decrease in leisure time activity (Siriopoulos et al., 1999). Male spousal caregivers subjectively measured their health based on the amount of leisure activities they participated in. As their loved one became progressively more dependent on their husbands, the male spousal caregivers had less timed to spend in leisure time activity, resulting in poorer health (Shanks-McElroy & Strobino, 2001).

One common theme that was expressed in both female and male spousal caregivers was related to the social isolation that occurred due to caring for their spouse. The caregivers admitted that their spouse had been the focus of their life and had a large role in their social, emotional, and overall well-being. Now that he/she was no longer able to act as this companion, the caregivers experienced loneliness and isolation (Sanders et al., 2008). They often admitted to feelings of lost companionship and affection. Male spousal caregivers often display some sort of emotional separation in their role as a caregiver by defining the role as more instrumental, task-oriented, and intellectual (Hubbell & Hubbell, 2002).

The physical and psychological health of spousal caregivers is often greatly affected as a result of the increase in stress and burden that is a consequence of caring for a loved one with
Alzheimer’s disease. In order to better prepare families to care for their loved ones with Alzheimer’s disease, it is vital for individuals who work in the healthcare arena to be aware of the different ways in which male and female spousal caregivers perceive caregiver burden as well as the physical and mental consequences that can occur.

Although many caregivers for family members with Alzheimer’s disease are spouses, it is important to consider adult children caregivers as well. With the rapid progression of the disease in the next decades to come, more and more individuals, regardless of age or sex, will be taking on the caregiver role for a family member with Alzheimer’s disease. The following discussion will analyze the adult child caregiver-care recipient relationship.
The Adult Child Caregiver-Care Recipient Relationship

Just as spouses often take on the role of caregiver for their loved one with Alzheimer’s disease, adult children also take on this role and it is important to recognize how this complex responsibility affects their health, both mentally and physically. Adult children make up the largest group of caregivers for individuals with Alzheimer’s disease and 57 percent of all caregivers are providing care for a mother, mother-in-law, father, or father-in-law (Alzheimer’s Association, 2008).

It has been postulated that there are dynamic differences in the way in which spouses and adult children react to the disease process of Alzheimer’s disease (Ott, Sanders, & Kelber, 2008). In fact, one study found that adult children caregivers for a parent with Alzheimer’s disease were more vulnerable to the stressors associated with the caregiving experience. In particular, daughters were more likely to have psychological problems as a result of the caregiving experience compared to sons (Golimbet & Trubnikov, 2001). When compared to spousal and adult son caregivers, the adult daughter caregivers were found to be more affected by the burden of caring for a loved one with Alzheimer’s disease (Chumbler et al., 2003). It has also been suggested that adult children caregivers were more likely to express guilt and regret as a result of caring for a parent with Alzheimer’s disease than spousal caregivers. The adult children caregivers were also more aware of the struggles of dealing with the healthcare field that those individuals with Alzheimer’s disease and their families face (Ott, Sanders, & Kelber, 2008).

It has been shown that adult children caregivers often experience denial and avoidance during the initial stages of caring for their loved one with Alzheimer’s disease and this eventually progresses to anger. As the disease progresses, these feelings turn to frustration,
burden, and sadness. As the disease course comes to an end, the dominant feelings are sadness, longing, loneliness, and resignation (Ott, Sanders, & Kelber, 2008).

A study developed and implemented by Lewis et al. (2005) found that only-child daughters, unmarried daughters, unemployed daughters, and daughters who lived in close proximity were more likely to take on the job as caregiver for their parents who were demented (Lewis et al., 2005). Although daughter caregivers have reported less physical health detriments as a result of the caregiving experience, the level of grief that they experienced was very comparable to spousal caregivers of individuals with Alzheimer’s disease (Berg-Weger et al., 2003).

A recent study that was conducted by Ward-Griffin et al. (2007) was developed in order to develop a better understanding of the dynamic relationship that exists between an adult daughter caregiver for her mother with Alzheimer’s disease. The study consisted of ten mothers who suffered from dementia and fifteen adult daughter caregivers. The mothers ranged in age from 75 to 98 years old and the daughters ranged in age from 35 to 63 years. Videotaped interviews were conducted on both mothers and daughters separately in a time span of nine months in order to record how the caregiver-care recipient relationship evolved as the disease progressed. Due to two mothers not completely both interviews, the resulting study group was decreased down to 13 caregiver-care recipient relationships. It was concluded that adult daughter caregivers deconstructed their relationships with their mothers and then rebuilt new understandings of their new role as a caregiver for their mother with Alzheimer’s disease. Results exemplified that there are different relationship dynamics between daughter caregivers and their mothers with Alzheimer’s disease. A custodial relationship focused more on the deficits of the relationship versus a cooperative relationship which focused on strengths of the
relationship. In the custodial based relationship, the adult daughter caregivers reported distress and dissatisfaction. In the cooperative based relationship, the adult daughter caregivers reported more satisfaction. These findings exemplify the need for health care professionals to be aware of the different relationships that can occur between the caregiver and the individual with Alzheimer’s disease and the need to approach each case in a very individualized personal manner.

There seems to be very little research that focuses on adult sons as caregivers. However, from the minimal research that is available, it has been concluded that adult son caregivers are less affected by the caregiving experience pertaining to both physical and psychological health and also experience less overall burden compared to spousal and daughter caregivers (Chumbler et al., 2003; Golimbet & Trubnikov, 2001). Although both spouses and daughters expressed a sense of a relational loss at the beginning of caring for their loved one with Alzheimer’s disease, daughters did report an improvement in the relationship with the care recipient after the onset of dementia (Ward-Griffin et al., 2007). However, the daughters did experience a greater amount of negative effects on their health, family life, and work life compared to adult son caregivers (Ward-Griffin et al., 2007). This same study concluded that spousal caregivers utilized support groups more than the adult children caregivers, which could have a significant impact on the well-being of the caregiver.

It is important to mention that spousal caregivers and adult child caregivers are experiencing different stressors in their lives and this could have a direct affect on the relationship with the care recipient with Alzheimer’s disease. Research does show that family caregivers who have less resources and time and more obligations experience a greater level of stress (Stephens et al., 2001; Ward-Griffin et al., 2007). Adult children caregivers, especially
daughters, are often times trying to juggle their own family and work at the same time they are trying to care for their parent with Alzheimer’s disease. Primary health care providers need to be aware of the differences in problems that different caregivers face when caring for a loved one with Alzheimer’s disease. It is the collaboration of support groups and counseling as well as educational resources that can assist adult children caregivers in the transition from being a child once cared for by his/her parents to now being the primary caregiver of their parent. More research is needed in order to assess the differences between daughter caregivers versus son caregivers as well as different ethnic populations.

The transition to caregiver for a family member with Alzheimer’s disease is a difficult task, regardless of whether it is for a spouse or a parent. If the level of caregiver burden is not monitored and controlled, the caregiver is more likely to resort to long-term care placement as the disease becomes progressively worse, leaving the individual with Alzheimer’s disease more debilitated. It is important to be aware of the stressors associated with caring for a family member with Alzheimer’s disease in order to prevent earlier placement in a long-term facility, which would exacerbate the already astronomical financial burden that Alzheimer’s disease places on society.
Factors that Lead to Long-Term Placement

It is important to understand not only the physical and psychological consequences that caregivers of individuals with Alzheimer’s disease experience, but to also understand the factors that eventually lead them to transfer their loved one to a long-term facility and how this affects the caregiver’s physical and psychological health. Caring for a family member with Alzheimer’s disease can often be a challenging task that is both physically and psychologically exhausting to the caregiver. Due to the fact that Alzheimer’s disease is a progressively deteriorating disease, there are often two inevitable outcomes to the in-home caregiving experience: death or placement of the loved one with Alzheimer’s disease into a long-term placement facility (Grant et al., 2002). Most caregivers react to this transition with feelings of guilt and a deep sense of grieving, which could negatively affect their health. Conversely, some caregivers experience feelings of relief and accomplishment at what they were able to do for their loved one and the caregiver’s health drastically improve after long term care placement. Regardless of the end result of moving a loved one with Alzheimer’s disease into a long-term care facility, the transition can often be a difficult experience for both caregiver and care-recipient (Grant et al., 2002).

Nursing home placement is an economic burden and is costly to both families and society (Yaffe et al., 2002). Alzheimer’s disease is the 3rd most expensive disease in the United States and annual costs have been estimated to be around $1000 billion (Fillit, 2000). This includes both direct and indirect costs and increases exponentially as the disease progresses and hospitalization or nursing home placement becomes more prominent. Of these costs, nursing home placement is the most expensive component of Alzheimer’s disease (Hux et al., 1998).
It has been shown that individuals that suffer from Alzheimer’s disease have an increased risk for nursing home placement (Eaker et al., 2002). Data shows that individuals with Alzheimer’s disease have a narrow time span from diagnosis to institutionalization, ranging from 2-6 years. Even more devastating is that 90 percent of individuals with dementia become institutionalized by the time of death (Smith et al., 2000).

Many factors pertaining to caregiver burden have contributed to earlier long-term care placement of the individual with Alzheimer’s disease. Many issues are contributory to one’s decision to transfer a family member who suffers from Alzheimer’s disease to a long-term care facility, including caregiver and care-recipient characteristics, cultural values, problem behaviors and cognitive decline as well the health status and burden level of the caregiver (Smith et al., 2002; Yaffe et al., 2002; Schulz et al., 2004). It is important to consider all these components together as a unit when analyzing the complex relationship between the caregiver and care-recipient and time to institutionalization.

Interestingly, it was concluded that caregiver distress in response to patient behavior was a large predictor of nursing home placement. Adult children caregivers, particularly daughters, resorted to transferring their loved ones to a long-term care facility in a shorter time span compared to other caregivers. This is significant because it has been suggested that the caregiver’s relationship with the patient was found to have the most significant direct affect on the caregiver’s level of burden and increased risk for long-term placement of the individual with Alzheimer’s disease (Annerstedt et al., 2000). Some of the more common behavioral problems of individuals with Alzheimer’s disease that increase the risk for long-term placement include depression and aggressiveness (Yaffe et al., 2002).
Although nursing home placement can relieve some of the responsibilities and burdens associated with caring for an individual with Alzheimer’s disease, the grief and overall stress of worrying about their loved one remains. Schulz et al. (2004) conducted a recent study in order to evaluate the overall impact that moving their family member to a long-term facility in order to be cared for had on the health of the caregiver. The study group consisted of 1,222 caregivers of all different ethnicities that had participated in the Resources for Enhancing Alzheimer's Caregiver Health (REACH) study. The median age of the caregivers was 63 years old and females comprised the majority of the study group. Surveys were administered and a control group and a treatment group were formed. The caregivers that were assigned to the treatment group received weekly social and behavioral interventions versus minimal support that the control group received. The caregivers were then evaluated at months 6, 12 and 18. It was concluded that the caregivers in the treatment group reported a lower level of burden compared to the control group. It was also found that race/ethnicity, increased caregiver burden, and the decline in cognitive function of the care-recipient were key indicators for earlier institutionalization of the individual with Alzheimer’s disease. Caregivers that were spouses expressed more anxiety and depression both before and after institutionalizing their spouse. This suggests that institutionalizing a family member with Alzheimer’s disease doesn’t necessarily indicate that the health of the caregiver, both physically and mentally, is going improve. The frequent visits along with the increased anxiety over adequate treatment of their family member often times exacerbate the already high anxiety that many caregivers face. However, this study also noted that caregivers that expressed feelings of being needed and appreciated by their care-recipients reported a lower level of burden as well as a lower rate of institutionalizing their family member with Alzheimer’s disease.
Many caregivers experience feelings of guilt and failure from placing their loved ones in a nursing home as well as increased worrying due to not being able to ensure adequate care for their loved ones (Mittelman et al., 2006). However, it is important to keep in mind that long-term placement can place the individual with Alzheimer’s disease at risk for increased morbidity due to being placed in an unfamiliar place away from his/her caregiver (Mace et al., 2001). Many of the individuals with Alzheimer’s disease experience a decline in functional and cognitive abilities due to a change in environment, which leads to even more guilt and worry from the caregiver (Schulz et al., 2004; Tornatore et al., 2002).

Some studies suggest that spousal caregivers experience a significant increase in depressive symptoms immediately following placement of their loved ones but no long-term chronic changes in depression (Mausbach et al., 2007). Spousal caregivers reported fewer serious medical symptoms immediately after placing their loved one in a long-term care facility and this reduction was sustained over time (Mausbach et al., 2007).

Contrary to many studies, some findings suggest that caregivers experience a significant improvement in both psychological and physical health 6-12 months following nursing home placement of their loved one (Mausbach et al., 2007). However, this study didn’t account for the different outcomes related to gender or kinship when analyzing the affect that long-term care placement can have on the caregiver. Grant et al. (2002) implemented a study that focused on spousal caregivers and found that the caregivers had a significant decrease in depressive symptoms as well as an improvement in medical conditions within a year of placing their loved one in long-term placement.

Adult children caregivers were less likely to co-habituate with their parent who had Alzheimer’s disease, which could be a reason for the higher level of burden as well as earlier
institutionalization of their parent with Alzheimer’s disease. The adult children caregivers were very aware of the condition of their parent with dementia; however, due to their living and work conditions, they were less likely to be available to help on an emergency basis after moving their parent from the home environment to a long-term care facility (Annerstedt et al., 2000). This ultimately led to feelings of inadequacy and frustration on the adult children caregivers due to not be available to travel to visit their parent when an emergent crisis arouse.

A study that was conducted by De Vugt et al. (2005) focused on behavioral and physiological symptoms of dementia and the effect this had on the level of caregiver burden and nursing home placement. Participants included 119 caregivers of individuals with Alzheimer’s disease. The caregivers and care-recipients were observed every six months for two years. At the beginning of the study, all care-recipients were living at home. The focus of the study revolved around time to nursing home placement. At each follow-up interview, the caregivers were asked to subjectively rate their level of distress from the different behavioral symptoms that their family member with Alzheimer’s disease was exemplifying. Concluding results showed that 41 percent of the individuals with Alzheimer’s disease were institutionalized during the two-year study. Although the behavioral and psychological symptoms of dementia did not directly predict nursing home placement, the distress that caregivers expressed from these symptoms was shown to be directly related to a shorter time interval from diagnosis to nursing home placement. This would suggest that health care providers should focus more on educating for caregivers on how to deal with these symptoms as opposed to focusing on ways in which to eliminate these behavioral symptoms. Instead of trying to change the behavioral symptoms that the care-recipient portrays, the focus should be on changing the caregiver’s perception of these behavioral symptoms. Kinship was found to be the only caregiver demographic characteristic in predicting
caregiver burden and time to nursing home placement. The daughter caregivers admitted to feelings of incompetence in caring for a parent with Alzheimer’s disease and expressed more feelings of distress as a result of the caregiving experience. Spousal caregivers were shown to have a stronger commitment to keeping their loved ones at home for as long as possible. These findings signify the need for interventions that are geared towards educating caregivers on effective strategies to better deal with certain behaviors that can occur in individuals with Alzheimer’s disease in order to decrease the risk for earlier placement in a long-term care facility (De Vugt et al., 2005).

On study that observed differences between ethnicity and time to institutionalization among Latino and Caucasian women caregivers found that the Latinas were less likely to institutionalize their relative with Alzheimer’s disease (Mausbach et al., 2004). The study included 264 female caregivers of Alzheimer’s disease with 154 being Caucasian and 110 being Latino. At the beginning of the study, 213 caregivers were randomly assigned to either a cognitive/behavioral psycho-educational class designed to alleviate caregiver distress or an enhanced support group that resembled community support groups. The remaining 44 caregivers participated in a telephone-based minimal support group and 7 caregivers were given minimal support. It was suggest by this study that the more-positive outlook of caregiving as well as less acculturation of many of the Latino participants were significant predictors in the lower rate of institutionalization compared to their Caucasian counterparts. It is important to mention that the Latino caregivers were younger, less educated, and more likely to be married than their Caucasian counterparts. However, this study utilized secondary analyses in order to account for the differences in care-recipient and caregiver characteristics (Mausbach et al., 2004). It was
postulated that this difference could be attributed to the Latino culture of more grounded traditional values that focuses on placing the family unit before the individual.

Along the lines of race and ethnicity, it has been suggested that the elderly African American population utilizes long-term care facilities less and chooses to care for their loved one with Alzheimer’s disease in the home for a longer period of time compared to Caucasian caregivers (Yaffe et al., 2002). These findings exemplify the importance for health care professionals to be aware of their patients’ cultural background in order to better meet their needs and to assist in their everyday care.

It is important for the primary care provider to be aware of caregiver burden and to assess their patients’ limits and assist them in the process of placing their loved ones in a long-term care facility. Primary care providers need to be more alert to symptoms of depression and stress that can occur in family members caring for their loved ones with Alzheimer’s disease. Even after institutionalization, caregivers continue to be at risk for detrimental health consequences. It is vital that these individuals receive interventions and counseling through the transition period of placing their loved one in a long-term facility (Schulz et al., 2004). The more educated caregivers are about certain behavioral problems and the progressive decline of the disease, the better prepared they can be when certain issues arise, which could ultimately lead to less deterioration of the health of both caregivers and care-recipients.

It is clear from the above-mentioned studies that the level of caregiver burden has a significant impact on nursing home placement of their family members with Alzheimer’s disease. What many theorists question is whether the level of burden experienced by caregivers for family members with Alzheimer’s disease is more pronounced compared to caregivers caring
for family members with non-dementia illnesses. The following discussion will assess the impact that different illnesses have on the caregiver’s physical and psychological health.
Caregivers of Individuals with Alzheimer’s disease Versus Non-Dementia Patients

Numerous studies have recently focused on assessing the impact that caregiving for a family member with a chronic illness has on the caregiver’s health. However, very few studies have been conducted that focus on the differences between dementia and non-dementia caregivers. Although it has been speculated that all caregivers of all types face many stressors related to the caregiving experience, certain stressors are more common in caregivers caring for a family member with Alzheimer’s disease versus caring for an individual with a non-dementia related medical condition.

According to a study done by the Alzheimer’s Association and National Alliance for Caregiving (2004), caring for an individual with Alzheimer’s disease is more physically and emotionally demanding than caring for individuals with a physical ailment. Along with the decline in physical and mental health of caregivers of individuals with Alzheimer’s disease, evidence also shows that caregivers of individuals with Alzheimer’s disease allot more time to care, experience more employment issues, spend less time in social activities, and experience more caregiver strain than caregivers for individuals with a non-dementia illness.

Ory et al. (1999) conducted one of the first studies in the late 90’s that focused on comparing dementia caregivers versus non-dementia caregivers. The main priority of this study was to examine the differences between these two groups of caregivers in terms of the impact of caregiving on the caregiver, the duties performed on a daily basis by the caregiver, and the affects that caregiving has on the caregiver’s social life.

The study sample was taken from a previous study through the National Alliance for Caregiving and American Association for Retired Persons and included 1,488 caregivers. The caregivers were providing care to a relative or friend who was at least age 50 years or older. Two
groups were formed based on whether the care-recipient suffered from Alzheimer’s disease/dementia or from a physical impairment/fragility/other chronic illness. A questionnaire was distributed and included 44 questions regarding the type of care provided, time spent providing care, the impact that caregiving had on the overall well-being of the caregiver, as well as social life and the utilization of outside resources.

In regards to demographics, many differences were found in this study regarding dementia caregivers versus non-dementia caregivers. Overall, women comprised the majority of caregivers regardless of whether they were caring for an individual with dementia versus caring for an individual with another chronic condition. It was found that caregivers of individuals with dementia were more likely to be spouses than non-dementia caregivers. The caregivers of individuals with dementia were significantly older compared to caregivers of non-dementia care-recipients. The care-recipients who suffered from dementia were also older than the non-dementia care-recipients. In terms of race, African American caregivers were more likely to care for an individual with dementia compared to Caucasian caregivers and Asian caregivers were less likely than their Caucasian counterparts to care for an individual with dementia.

Ory et al. concluded that caregivers of individuals with dementia were more affected both physically and mentally by the caregiving experience than caregivers of non-dementia care-recipients. Caregivers for individuals with dementia contributed more hours per week towards caring for the care-recipient as well as assisting with more ADL and IADL. Caregivers for individuals with dementia were more likely to utilize external formal resources compared to the caregivers of individuals with a non-dementia chronic illness. Ory et al. suggested that the higher level of strain that the caregivers for individuals with dementia experienced could possibly be related to the behavioral problems that many individuals with dementia, specifically Alzheimer’s
One major weakness of this study was that the establishment of the dementia caregiver study group was based on a subjective caregiver telephone survey of the care-recipients symptoms. The caregivers were simply asked if their care-recipient suffered from Alzheimer’s disease or dementia, which wouldn’t necessarily exclude an individual who was simply suffering from delirium associated with an acute illness. There is a great need for more longitudinal studies in order to monitor the progression of the caregiving experience.

A recent study that was conducted by Bertrand et al. (2006) observed the differences in stressors related to caregiving based on care-recipient’s diagnostic illness. The study sample included 349 community dwelling women age 65 years or older. The women were assigned to one of two groups based on whether they were a dementia caregiver versus a non-dementia caregiver. A caregiver questionnaire was distributed that collected information that pertained to caregiver demographics, caregiver duties pertaining to ADL and IADL, and care-recipient problems. This study concluded that the caregiving experience did differ depending on if the care-recipient had Alzheimer’s disease versus a non-Alzheimer’s disease diagnosis. Caregivers for individuals without a dementia-illness were found to report less stress and a lower level of burden. Bertrand et al. hypothesized that the increase in stress levels of caregivers for individuals with Alzheimer’s disease could be due to providing more assistance with ADL and IADL for the care-recipient. Bertrand et al. concluded that health care professionals could potentially overestimate or underestimate the amount and type of stressors that caregivers experienced by grouping all caregivers into one homogenous group.

Another recent article by Pinquart and Sorensen (2006) focused on a similar concept as the above-mentioned article. The focus of their research was based on the question of how caring for an individual with Alzheimer’s disease versus caring for an individual with a physical
impairment influenced the level of caregiver burden. Pinquart and Sorensen suggested that there are five different unique issues involved in caring for a family member with dementia of the Alzheimer’s type that result in a different level of caregiving burden. They included: dementia-related behavioral problems, disorientation, and alterations in personality; an increased need for supervision which can result in a diminished social life for the caregiver; the isolation that caregivers of individuals with Alzheimer’s disease experiences due to the care-recipient’s behavioral issues; the lack of ability of the care-recipient to express gratitude; and the slow, progressive deterioration of the care-recipient. In order to test these concepts, Pinquart and Sorensen conducted a meta-analysis involving 96 studies that were identified from the developmental and gerontological literature through electronic databases. These studies were utilized in order to assess caregiver perceived stress, depression, and overall well-being pertaining to both physical health as well as mental health. Caregivers of individuals with Alzheimer’s disease had higher levels of perceived stress, experienced significantly more behavioral problems from the care-recipient, spent more hours per day caring for the care-recipient and were more likely to feel trapped in the caregiving role than caregivers of individuals with a non-dementia illness. However, it is important to note that care-recipients with dementia were older and more likely to be living with the caregiver. In concluding, Pinquart and Sorensen stated that caregivers for family members with dementia in their meta-analysis consistently portrayed higher levels of stress as well as a higher risk of developing poor psychological and physical health. This would suggest that caregivers of individuals with Alzheimer’s disease could possibly benefit from interventions involving psychosocial therapy more than caregivers of individuals with physical impairments.
A recent study by Huang et al. (2009) conducted a project that analyzed the differences in caring for an individual with Alzheimer’s disease versus caring for an individual who had experienced a stroke. Huang et al concluded that caregivers for individuals with Alzheimer’s disease reported a higher level of burden which led to more reports of depressive symptoms than caregivers for individuals who had suffered from a stroke. Individuals with Alzheimer’s disease had more behavioral problems and the caregivers of these individuals were shown to have a poorer level of overall general health and less emotional support than caregivers for individuals who had suffered from a stroke.

Clark and King (2003) were also interested in comparing caregivers of individuals with Alzheimer’s disease to caregivers of individuals who have suffered from a stroke. Clark and King noted that although caregivers for these two groups of debilitating conditions experienced similar tasks related to the caregiving experience, there were some significant differences in the progression of these conditions. Individuals suffering from Alzheimer’s disease experienced a gradual progressive decline that affects both their cognitive and their functional capacity. On the other hand, individuals that suffered from a stroke experienced a very acute onset of the condition that could potentially leave the individual physically and psychologically debilitated. Whereas an individual who had suffered from a stroke could eventually regain some functional capacity through the recovery process, an individual with Alzheimer’s disease progressively worsened.

These differences could ultimately impact the level of burden that caregivers for these individuals experienced. Clark and King used data from a previous larger study to conduct a cross-sectional secondary analysis. The recruitment of caregivers and their care-recipients took place among five different adult day care facilities. The final study group consisted of 18
caregivers of individuals who had suffered from a debilitating stroke and 22 caregivers of individuals with Alzheimer’s disease. Caregiver depression and fatigue were utilized as measuring devices in order to assess the level of caregiver burden. The caregivers were also questioned about the effects that the caregiving experience had on the family unit as well as their utilization of outside formal and informal resources.

Concluding results contradicted conclusions made from previous studies that focused on similar research hypothesis. Clark and King concluded that although caregivers of individuals with Alzheimer’s disease reported more behavioral and memory problems from the care-recipients than caregivers of individuals who suffered from a stroke, both groups of caregivers reported similar levels of depression and fatigue. Clark and King speculated that this could be due to the fact that the caregivers of individuals with Alzheimer’s disease in their specific study were more educated about the disease process as well as the behavioral and psychological symptoms associated with Alzheimer’s disease than study subjects from previous studies. One significant finding from this study was that the caregivers of individuals with Alzheimer’s disease were more likely to have a college education, which has been found to be an independent factor associated with less negative effects of caregiving. It should also be noted that the caregivers of individuals with Alzheimer’s disease had been caring for their care-recipients for a longer period of time, roughly a year and a half longer than the caregivers of individuals who had suffered from a stroke. Caregivers of individuals who had suffered from a stroke reported less familiarity with the behavioral issues portrayed by the care-recipients and this could be due to the fact that the focus of rehabilitation of individuals who have suffered from stroke often revolves around the physical impairments as opposed to the psychological component involved in stroke. This could explain why the caregivers of individuals who had suffered a stroke lack
knowledge pertaining to the psychological aspect that occurs in those who have suffered from a stroke, which could lead to more frustration from the caregiver’s perspective.

Taking on the role as a primary caregiver for a family member or friend can be a difficult experience. Many of these individuals are faced with impairments in the physical, cognitive, and psychological functionality of the care-recipient, regardless of the etiology of the disease. However, research consistently shows that caregiver burden differs depending on the disease-state of the care-recipient. It is vital for health care professionals to be aware of these differences in order to provide support and anticipatory guidance to these caregivers. This will lead to a smoother transition into the caregiver role and potentially keep individuals who suffer from a debilitating illnesses in the community to be cared for within the home environment and in the familiarity of their family and friends. The following discussion will assess ways in which health care professionals, specifically physician assistants, can contribute towards caring for both the individual with Alzheimer’s disease as well as the caregiver.
The Physician Assistant’s Role

Providing care for a loved one with Alzheimer’s disease can be a stressful experience and many caregivers of these individuals begin to experience personal health deterioration. More families are now caring for these individuals in their own homes, providing roughly 80 percent of the care to their loved ones suffering from Alzheimer’s disease (Yaffe et al., 2008). In the last two decades, many studies have been conducted that illustrate that caring for an individual with Alzheimer’s disease can result in increased morbidity and mortality rates of caregivers.

It is important to educate health care professionals on the complexity of Alzheimer’s disease. A lack of knowledge and time on the health care professional’s side can lead to undiagnosed cases of Alzheimer’s disease as well as inefficient treatment. Unfortunately, many clinicians fail to recognize cognitive decline in their patients during the office visit (Boise et al., 2004; Camicioli et al., 2000). Many health care providers state that they have many different constraints, such as lack of time, which make it extremely difficult to evaluate the complex symptoms that can occur in the beginning stages of Alzheimer’s disease (Boise et al., 2004). A recent study conducted by Boise et al. (2004) concluded that there are two main reasons why health care providers admit to neglecting the assessment of cognitive decline. The first one pertains to the time constraint. Many health care providers cut their office visits shorter and only focus on the current issue that brought the patient in. This leaves very little time for a proper cognitive assessment of the patient. The second reason why there is a lack of proper assessment is the perception that many health care providers have towards a diagnosis of Alzheimer’s disease. They feel it is a progressive disease that has no cure or effective treatment (Boise et al., 2004).
Van Hout et al. (2006) conducted a recent study that observed the way in which health care providers disclose a diagnosis of dementia to their patients and their caregivers and how both parties react to this diagnosis. The study group consisted of 64 health care practitioners and 107 patients with dementia from the Netherlands. Health care providers assessed their patients for dementia using the Dutch College of General Practitioners (De Bruyne et al., 1991). This diagnostic manual for dementia uses criteria from the Diagnostic Statistical Manual of Mental Disorders to assess cognitive functioning. The patient was assessed based on 11 cognitive functions and the level of care required by his/her caregiver. The general practitioner’s performance was also reviewed and recorded. Van Hout et al. concluded that health care providers are a key component in the disclosure of a dementia diagnosis to both the patient and the family. They found that the health care providers from their study only reported a known diagnosis of dementia to 42 percent of their patients and 82 percent of the caregivers. However, although the primary care provider was reporting the diagnosis to the caregivers more often than to the patients, less than half of the caregivers reported receiving adequate information regarding behavioral issues associated with dementia. This study exemplifies the need for primary health care providers to be more educated in diagnosing and treating individuals with dementia and their caregivers. The more confident that the general practitioner felt towards his/her knowledge base pertaining to dementia, the more likely he/she was to disclose a diagnosis of dementia to the patient.

Physician assistants can have a significant role in the lives of both the families and the patient who suffer from an Alzheimer’s disease diagnosis. Physician assistants often have more time allotted to spend with patients and can offer more educational and counseling advice in the family care practice setting.
The health care professional’s role, such as a physician assistant, begins with the initial diagnosis of Alzheimer’s disease and establishment of an individualized treatment plan. Taking the time to educate both the patient and the family can greatly impact future complications (Small et al., 1997). The physician assistant should assess the level of daily functioning and the current cognitive status. Any behavioral issues should also be documented. The patient should be reassessed every 6 months in order to ensure that the physician assistant is following the progression of the disease. Unfortunately, many individuals with Alzheimer’s disease also have other co-morbid conditions which need to be strictly monitored in order to ensure the safety and optimal functioning of the patient. The physician assistant should also be aware of the community resources, such as support groups and daycare centers, which are available in order to further assist the family and patient in coming to terms with the diagnosis of Alzheimer’s disease.

The primary caregiver’s physical and mental health should also be assessed and, if needed, counseling and educational sessions should be provided (Cummings et al., 2002). A key study done in 1995 concluded that caregivers of individuals with Alzheimer’s disease suffer more physical and psychological health than the general population. These caregivers also have a higher intake of prescription drugs than non-caregivers (Schulz et al., 1995). In order to minimize caregiver stress and maximize the caregiver-care recipient relationship, anticipatory guidance is a key component of the office visit. Physician assistants can utilize the Caregiver Burden Scale in order to assess each caregiver on individualized basis and then to provide counseling for caregivers that have a higher level of burden. This is a self-administered questionnaire that can be used in the office setting for assessing the level of burden that the caregivers are experiencing (Cummings et al., 2002).
It has been reported that many caregivers of individuals with Alzheimer’s disease feel that their loved one’s needs, such as monitoring medications and symptoms, are not adequately treated by the primary care provider. The caregivers also reported that they feel there is a lack of interventions and emotional support pertaining to their own unmet needs, both physically and emotionally (Portinsky, 2001). Although Alzheimer’s disease is a dynamic condition, progressively changing the individual it affects, the physician assistant can act as a stable support system for both the family and individual with Alzheimer’s disease. As the disease progresses and the caregiver takes on more responsibilities, the physician assistant is going to have to be aware of how both his/her patient as well as the primary caregiver is being affected both physically and mentally by this disease.

Considering that higher level of burden and depression of the caregiver can lead to earlier institutionalization of the individual with Alzheimer’s disease, it becomes imperative for primary care providers to assess the health of the caregivers of their patients in order to avoid this situation (Thomas et al., 2004). It has become quite evident that many primary care providers focus solely on the treatment of the individual with Alzheimer’s patient and indirectly disregard family caregivers. What is even more devastating is that many primary care providers recognize their lack of acknowledgment of the caregiver. However, due to the time constraints, they fail to do anything about it (Fortinsky et al., 2001).

Many caregivers feel that the primary care provider is unavailable for adequate treatment of their loved one with Alzheimer’s disease. They are unaware of the overall distress that the caregiver experiences on a daily basis (Cherry et al., 2004; Turner et al., 2004). Overall, many general practitioners report feeling comfortable in the treatment of patients with dementia,
however, the actual diagnosis and disclosure lead many of them to feel apprehensive in their abilities to deal with the patient and the families (Van Hout et al., 2006; Werner et al., 2004).

Many primary care providers, including physicians, physician assistants, and nurse practitioners, experience challenges when diagnosing their patients with Alzheimer’s disease, especially when there are other co-morbidities. These challenges include feelings of frustration and denial from both the family and the patient in regards to the diagnosis. Primary care providers also reported difficulties in making a definitive diagnosis of Alzheimer’s disease when there were other co-morbidities. Trying to effectively treat their patients as well as provide support to the family was often seen as time-consuming by most primary care providers (Yaffe et al., 2008). In fact, a recent study found that primary care providers wanted more problem and case-based educational seminars pertaining to Alzheimer’s disease and they felt that this would help them to better understand the obstacles that many of their patients and caregivers are experiencing (Wilkinson et al., 2004).

Primary care providers also admitted to a lack of knowledge about the resources that were available to individuals with Alzheimer’s disease and their families within the community. Yaffe et al. (2008) found that the primary care providers that they studied felt that they were not able to provide the assistance and support that many of the caregivers and families of their patients with Alzheimer’s disease desired. Instead, they often referred these patients to the Alzheimer’s Association because they felt that they had more to offer and were more knowledgeable about the community resources (Yaffe et al., 2008). This lack of knowledge and underuse of outside community resources is an obstacle that could possibly be the missing link to the problem that many caregivers express about dealing with primary care providers.
Primary care providers express many difficulties in the care and management of their patients with Alzheimer’s disease, including disclosing the diagnosis to the patient, assessing and treating the behavioral problems that occur as the disease progresses, and coordinating support services for the family and primary caregivers (Turner et al., 2004). Many health care professionals found communication very difficult with their patients with Alzheimer’s disease. Considering that 85 percent of individuals with Alzheimer’s disease exhibit language and communication disturbances, it is vital that health care professionals key in on these components during the patient’s visit. This will assist the primary care provider in designing and implementing individualized treatment plans for both the family and the individual with Alzheimer’s disease based on the degree of communication deterioration (Orange & Bouchard, 2000). Without effective communication between health care professionals and their patients with Alzheimer’s disease it becomes nearly impossible to establish efficient patient and caregiver care. Many of the general practitioners, especially the older males, expressed a negative attitude associated with dementia and felt that their patients with dementia were best treated by a specialist (Van Hout et al., 2006).

One important detail that health care professionals as well as the primary caregiver must acknowledge is that the individual with Alzheimer’s disease should be included in the decision-making process regarding treatment and care. Many individuals in the early stages of Alzheimer’s disease communicate the desire to take part in decisions concerning their treatment (Hirschman et al., 2005). Physician assistants should encourage primary caregivers to continuously discuss medical issues with the individual with Alzheimer’s disease. An assessment of the individual’s with Alzheimer’s disease level of understanding will then determine how much autonomy is appropriate.
Many families and caregivers felt that their general practitioner was often very dismissive of the diagnosis of Alzheimer’s disease and often overlooked many of the problems that the patient was experiencing, exemplifying a very hopeless outlook toward the diagnosis of their patient (Van Hout et al., 2006). These findings are very significant in that general practitioners need to be better educated on the diagnosis and treatment of Alzheimer’s disease because earlier treatment is vital in order to better prepare both family and patient. General practitioners need to identify the level of burden that the caregivers of their patients are experiencing, especially depression and anxiety. They need to offer advice on how to better manage the care-recipient’s health as well as counseling on how to effectively cope with the behavioral problems that occur in the individual with Alzheimer’s disease as the disease progresses (Parks & Novielli, 2000). It becomes important for the physician assistant to recognize the complexity of the relationship that exists between the caregiver and care-recipient and to key in on opportunities to educate the caregiver on how better to manage both his/her own health as well as the health of the individual with Alzheimer’s disease.
Conclusion

In reviewing the literature, it is quite obvious that Alzheimer’s disease affects all people in some direct or indirect manner regardless of age, gender, or ethnicity. In the year 2000, it was estimated that there were 411,000 new cases of Alzheimer’s disease and this number is expected to increase to 454,000 new cases a year by 2010, 615,000 new cases a year by 2030, and 959,000 new cases a year by 2050 (Herbert et al., 2001). Due to the progressive increase in older adults, Alzheimer’s disease diagnoses are continuously escalating and the repercussions of this devastating fact will have a drastic affect on both the family and the individual with Alzheimer’s disease.

Due to the increasing prevalence of Alzheimer’s disease and the economic burden that this diagnosis can have, many families become the primary caregiver for their loved one with Alzheimer’s disease. Although this situation can have some very rewarding experiences, the burden that accompanies caring for an individual with Alzheimer’s disease can have numerous affects on the caregiver’s physical and psychological health. Family relationships can significantly change in response to the demanding care that individuals with Alzheimer’s disease require. It is for these reasons that health care providers need to become more educated in not only diagnosing and treating their patients with Alzheimer’s disease but also being aware of the caregiver’s status and being prepared to provide the family with outside resources for support and counseling.

Numerous studies have examined caregiver burden as well as the relationship differences in caregiving outcome. The literature incessantly suggests that providing care for a family member with Alzheimer’s disease can affect one’s physical, psychological, financial, and social well-being. Although there are some conflicting data pertaining to the degree of declining health
of caregivers, one theory that seems to be consistent is that there is a direct correlation between Alzheimer’s disease caregiving and deterioration in mental health of caregivers. Increased anxiety and depression are commonly observed in caregivers of individuals with Alzheimer’s disease across the literature.

Many scholars have studied the differences in kinship between the caregiver and care-recipient and the varying degrees of burden experienced by the caregivers. Literature consistently concludes that adult children caregivers and spouses make up the majority of caregivers for individuals with Alzheimer’s disease. How these individuals react to the caregiving experience are often times very different from person to person. This is an important concept that needs to be recognized by health care providers and they should be cautious in overgeneralizing their perceptions in caregiver burden. Although spousal caregivers are more vulnerable to the stresses that develop from caring for a spouse with Alzheimer’s disease, adult children caring for their parents have their own set of unique obstacles pertaining to the caregiving experience (Clyburn et al., 2000).

One factor that much of the literature fails to account for when analyzing the health and psychological decline in caregivers as well as their perception of burden is ethnicity and cultural background. Different cultures have different attitudes and beliefs on how the family unit functions as well as their role in caring for the members of their family. Cultural beliefs could possibly have a significant impact on the level of burden that caregivers experience. Future studies will need to focus on the significance that cultural beliefs and practices can have on the caregiver-care recipient relationship.

Throughout the literature, a common theme that is portrayed in many of the studies is caregiver burden. Caregiver burden has been shown to be a predictor in long-term care
placement of the individual with Alzheimer’s disease. It is vital to assess the level of caregiver burden in order to provide interventions to assist the caregiver. By alleviating caregiver burden, the individual with Alzheimer’s disease is more likely to remain in the home environment for a longer period of time. Early screening methods that can identify caregiver burden are crucial in guiding caregivers through the stages of acceptance and understanding of the disease.

Establishing interventions that can support caregivers in dealing with some of the more problematic behaviors associated with Alzheimer’s disease can be a challenge that many health care professionals encounter. Considering that behavioral and psychological symptoms of dementia have been identified as key contributors to caregiver burden, anticipatory guidance can be implemented by health care professionals in order to prepare caregivers on what to expect and suggestions can be offered that can assist caregivers in dealing with these issues.

Active coping skills and support groups have a positive impact on the day-to-day stressors associated with caring for an individual with Alzheimer’s disease. Support groups can give caregivers the opportunity to interact with others who are experiencing similar problems. Health care professionals can be a key advocate for caregivers by being aware of local resources, such as support groups and the local Alzheimer’s Association, and encouraging caregivers to get involved in these organizations.

In conclusion, the dynamic relationship that exists between the caregiver and care-recipient is constantly changing as the progressive nature of Alzheimer’s disease takes its course. Considering that the individual with Alzheimer’s disease eventually becomes completely dependent on his/her caregiver, the physical and psychological health of the caregiver should be considered by health care professionals that are treating their patients with Alzheimer’s disease. Caregiver characteristics as well as the uniqueness of caring for an individual with Alzheimer’s
disease should be taken into consideration when providing care and assistance to families and patients affected by the disease. Future research is vital in order to begin dissecting the various dynamic relationships that can exist between the caregiver and care-recipient as well as to developing effective interventions to assist caregivers in caring for individuals with Alzheimer’s disease. Alzheimer’s disease doesn’t have to evoke feelings of lost identities and hopelessness. By establishing guidelines for treating both the patient and the caregiver in the health care setting, effective relationships can be established in order to live a manageable life with Alzheimer’s disease.
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Abstract

The **objective** of this literature review is to recognize the physical, psychological, and social impact placed on caregivers for individuals with Alzheimer’s disease. **Methods:** A literature review was performed using PubMed to identify topics relating to the purpose of the literature review. **Results:** Caregivers of individuals with Alzheimer’s disease are both physically and psychologically impacted in a negative way due to caregiver burden. Caregiver burden and long-term care placement of the individual with Alzheimer’s disease has been shown to be directly correlated. **Conclusion:** There are over 10 million adults acting as informal caregivers for individuals with Alzheimer’s disease. The burden that accompanies caring for an individual with Alzheimer disease can significantly impact the caregiver’s general health. It is vital that health care providers implement pre-emptive measures, such as risk-assessment and counseling, when dealing with their patients as well as the family members that endure a diagnosis of Alzheimer’s disease.