Examining the Experiences of Caregivers During the Diagnosis of Alzheimer’s Disease and Related Dementias

Thesis

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ABSTRACT

Memory loss disorders, such as Alzheimer’s disease and other dementias, are difficult to diagnose and individuals and families can wait years to receive a definitive diagnosis.

Without a diagnosis, questions arise as to when these individuals will be provided information about their condition and whether they will have access to disease-specific resources, such as those offered through the Alzheimer’s Association. The majority of the existing research that has been conducted on the diagnostic process for dementia has focused specifically on exploring physician attitudes and practices. As such, little is known regarding the needs of individuals with dementia and their family caregivers following this often devastating diagnosis. In this study, the researchers examined caregivers’ experiences with the diagnostic process and with accessing information and community resources. A convenience sample was drawn from caregivers identified through the Alzheimer’s Association (N=106). Participants completed either a 25-item written or online version of the questionnaire. A cross-sectional survey design was utilized to investigate the experiences of families during and following the diagnostic process for dementia. Survey items focused on the following: demographic and contextual variables; characteristics surrounding the diagnosis including the type of diagnosis, support service knowledge and use of community resources; and the caregiving role. The results of this study indicated that the majority of individuals were
receiving diagnoses within one year of pursuing a memory loss diagnosis; however, caregivers felt they were not adequately supported at the time of diagnosis, nor up to one year following diagnosis. Caregivers stated that they were not provided enough information at the time of diagnosis about the disease or how to provide care for an individual with memory loss. A year following diagnosis, the majority of caregivers still felt they did not understand the disease or how to provide care for an individual with memory loss, nor were they aware of what support services were available within their communities. Results of this study indicate that more could be done during the diagnostic process to help caregivers understand dementia and to learn about and connect with available support supports that can provide education and care assistance to dementia caregivers. It may be the case that models of care that provide more comprehensive services at the time of diagnosis and in the months and years following diagnosis yield better outcomes for family dementia caregivers.
DEDICATION

This study is dedicated to my grandparents, Charles and Laura Mae Lomax of Oakwood, Illinois. Chuck and Laura raised seven children, had ten grandchildren and seven great-grandchildren. Chuck was an electrician, and he served in the US Army during the Korean War. Laura taught English and literature. Chuck passed away April 13, 2009. He had Alzheimer’s disease. Laura resides at Pleasant Meadows Christian Village. She has dementia. She has long forgotten that I am her granddaughter, and while she may not know what I am to her—I hope she will always know me as a person who loves her.
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INTRODUCTION

Worldwide, there are an estimated 35 million individuals living with some form of dementia (Alzheimer’s Disease International, 2009). Dementia is a general term describing a group of disorders in which memory and thought processes become impaired. Dementia can be caused by many different disorders, but approximately 70% of cases are caused by Alzheimer's disease (AD). AD is a progressive and fatal brain disease, for which there is currently no cure (Alzheimer’s Association, 2009).

Although there is not one event that defines the beginning of dementia caregiving, it is often begun prior to diagnosis. Caregiving has been identified by the beginning of assistance with at least one activity of daily living (Gaugler, Zarit & Pearlin, 2003). The National Alliance for Caregiving estimates there are at least 43.5 million caregivers age 18 and over (19% of all adults) in the United States who provide unpaid care to an adult family member or friend who is age 50 years or older (2009). Currently, the estimate of those caregivers who are specifically providing care to an individual with dementia is just under 11 million (Alzheimer’s Association, 2010).

The process of getting a diagnosis of dementia can be overwhelming and even frustrating for families. Dementia has been described as the modern epidemic of later life, and is the most feared diagnosis by older adults (Bond & Corner, 2001). On top of
dealing with a devastating diagnosis, information and support that individuals and families receive during and following such diagnoses are often incomplete and inadequate. In some cases, individuals and families can wait years to finally receive a definitive diagnosis, further delaying their ability to connect to available support resources (Boise, Morgan, Kaye & Camicoli, 1999). Family members, the patient with suspected memory loss, and the doctor that is assessing for dementia can contribute to delays in the diagnosis of dementia (Boise et al., 1999; Bradford, Kunik, Schulz, Williams & Singh, 2009).

Then once diagnosed, individuals with AD and related dementias often need assistance with many components of their daily living activities (Alzheimer’s Association, 2009). Family caregivers are vital in providing informal care, or coordinating providers to assist with care, to these individuals that have been diagnosed. Caregivers provide invaluable services such as assistance with daily living tasks (preparing meals, bathing, dressing), transportation, and overseeing finances to family members or a friend with the disease. The cost for the United States to pay for these individuals’ care had they not had a caregiver would be close to 144 billion dollars (Alzheimer’s Association, 2010). Caregivers provide assistance to an already stressed national healthcare system, however, if caregivers are not properly supported through respite programs which allow caregivers to have breaks from their role as care provider, the stress of caregiving can challenge their physical, social, and emotional well-being (Pinquart & Sorensen, 2003; Son et al, 2007; Vitaliano, Zhang & Scanlon, 2003). In such cases, support services become essential for families (Sussman & Regehr, 2009). Despite
wanting and needing support services, caregivers are often unsure of the availability of such services and the way to connect with providers such as the Alzheimer’s Association (Adams, 2006). Many caregivers never end up accessing available services, mainly because of a perceived lack of need or lack of awareness (Broadaty, Thomson, Thompson & Fine, 2005).

To date, the majority of research on the subject of dementia diagnosis focuses on physician’s decisions on how and when to disclose diagnosis and to whom the diagnosis would be given (Bamford et al., 2004; Johnson, Bouman, & Pinner, 2000; Kissel & Carpenter, 2007). Questions still remain on what information these caregivers need during and after diagnosis, and how these caregivers come to connect to available support services within their communities. While many caregivers are interested in receiving information about providing care and available resources, they often do not receive it (Laakkonen et al., 2008). Additionally, many caregivers feel this information should come from the physician at diagnosis, but often times it does not (Ploeg et al., 2009). Without education and information, caregivers are left to fend for themselves in navigating what the care needs will be for the individual as the disease progresses, and how to obtain assistance in managing their care.

Researchers developed this study to further understand the experiences of caregivers during the diagnostic process, specifically looking to see whether or not families were experiencing challenges to receiving a diagnosis, and to identify what caregivers’ needs were following diagnosis. Additionally, the researchers questioned
how caregivers learned about available support services, and where that information came from to aid them in providing care to a person with dementia.
CHAPTER 2

LITERATURE REVIEW

Alzheimer’s Disease and Related Dementias

Dementia is a general term describing a group of disorders in which memory and thought processes become impaired. Dementia can be caused by many different disorders, but about 70% of cases are due to Alzheimer’s disease (AD). AD is a progressive and fatal brain disease, for which there is currently no cure. It is the sixth leading cause of death in the United States. A new case of AD develops every 70 seconds, and costs in the U.S. healthcare system to care for individuals with the disease exceeded 148 billion dollars last year (Alzheimer’s Association, 2009).

While there are 40-50 different types of dementia that are known, there is a degree of heterogeneity in the symptoms associated with the diseases that cause dementia. Dementia is a loss of brain function that occurs with certain diseases. Dementia affects memory, thinking, language, judgment, and behavior. Dementia usually first appears as forgetfulness. Most types of dementia are nonreversible (degenerative) and will never improve once they have started progressing (Mayo Clinic, 2010).
Alzheimer’s disease is highly related to an individual’s age, family history of the disease, and genetics of the individual. Most individuals with AD are 65 years of age or older, which accounts for 1 in every 8 adults 65 and older. After age 85, the risk reaches nearly 50 percent or every 1 in 2 will have AD. Having a family member with the disease increases risk by 10 percent, whereas having a family member with young onset AD, an individual diagnosed under age 65, increases hereditary risk to 50 percent (Alzheimer’s Association 2009).

Common symptoms of AD include 1) memory changes that disrupt daily living, 2) challenges in planning or solving problems, 3) difficulty completing familiar tasks at work, at home, or at leisure, 4) confusion with time or place, 5) trouble understanding visual images and spatial relationships, 6) new problems with words in speaking or writing, 7) misplacing things and losing the ability to retrace steps, 8) decreased or poor judgment, 9) withdrawal from work or social activities, 10) and changes in mood and personality (Alzheimer’s Association, 2009).

Early-Onset Alzheimer’s disease, also known as Young-Onset Alzheimer’s disease, is characterized by individuals diagnosed with AD under the age of 65. Many individuals with Early-Onset are diagnosed in their 40s and 50s and experience the same symptoms as someone diagnosed with AD over age 65. However, Early-Onset progresses at a much quicker rate than traditional AD—when the individual is diagnosed at 65 years of age or older (Alzheimer’s Association, 2009).
Vascular dementia is considered the second most common type of dementia. It develops when impaired blood flow to parts of the brain deprives cells of oxygen. This situation is sometimes referred to as “post-stroke dementia”. Symptoms differ from AD in terms of impairment. The decline of activities of daily living which occur in “steps, where there is a fairly sudden, noticeable change in function, rather than the slow, steady decline usually seen in AD”. Additionally, individuals with vascular dementia experience physical symptoms associated with strokes, such as sudden weakness and difficulty speaking (Alzheimer’s Association, 2009).

Frontotemporal dementia is a rare disorder that affects the front (frontal lobes) and the sides (temporal lobes) of the brain; additionally it is common for these areas in the brain to shrink. There is no specific abnormality associated with all cases of Frontotemporal dementia, but in one type called Pick’s disease, there are sometimes abnormal microscopic deposits called Pick bodies. Symptoms for Frontotemporal dementia include a more rapid onset than AD, feelings disassociated with situations they are experiencing, and personality, judgment, planning and social functioning tend to be affected early in onset of the disease (Alzheimer’s Association, 2009).

Dementia with Lewy Bodies is known so by abnormal deposits (Lewy Bodies) of a protein called alpha-synuclein that form inside the brain’s nerve cells Dementia with Lewy Bodies’ symptoms include excessive daytime drowsiness, cognitive symptoms and abilities fluctuating from good to bad throughout the day, shuffled walking, visual
hallucinations, and in about 50 percent of cases, it is associated with a condition called rapid eye movement (REM) sleep disorder (Alzheimer’s Association, 2009).

Multi-Infarct Dementia is caused by a series of strokes that damage or destroy brain tissue. Multi-infarct dementia usually affects people between the ages of 60 and 75, and men are slightly more likely than women to have this disease. The most significant risk factor for multi-infarct dementia is high blood pressure. Symptoms of Multi-Infarct dementia include laughing or crying inappropriately, shuffled steps, and mini-strokes also known as TIAs (transient ischemic attacks) which can cause slurred speech and weakness in arm or leg (Alzheimer’s Association, 2009).

**Prevalence of Problem**

The Alzheimer’s Association (2009), a primary source for ongoing research and information about dementia, reports that in the United States 5.3 billion people specifically that have AD. This is 13% of the older adult (65 and older) population. In Ohio alone, there are approximately 230,000 individuals living in the state with AD (Alzheimer’s Association, 2009). This number is expected to reach between 250,000 for Ohio by 2025, as the aging population continues to grow by 6% in Ohio each year (Alzheimer’s Association, 2009; Health Policy Institute of Ohio, 2009; Center for Community Solutions, 2009).

Additionally, approximately 1 in 10 of those individuals with AD has Early-Onset. This accounts for nearly 500,000 people in the United States diagnosed with AD
under the age of 65. While there is not a clear estimate of what the prevalence is of each
dementia, the 2002 Aging, Demographics, and Memory Study (ADAMS) found that 70%
of all dementia cases were AD, 17% of cases were vascular dementia, and the remaining
types of dementia were represented with the lingering 13%.

Women are more likely than men to have AD and other dementias. Based on
estimates from the ADAMS study, 14 percent of all people aged 71 and older have
dementia (Alzheimer’s Association, 2009). The estimate is that 2.4 million women and 1
million men aged 71 and older have a form of dementia (Alzheimer’s Association, 2009).
Many studies of the age-specific incidence of AD show no significant difference for
women and men (Bachman et al., 1993; Fillenbaum et al., 1998; Fitzpatrick et al., 2004;
Kukull et al., 2002). Therefore, it appears that gender is not a risk factor for AD or other
dementia when considering age. Essentially, women are more likely to have AD and
other dementias because they live long enough to develop these conditions and generally
live longer than men (Plassman et al., 2007).

African-Americans are frequently reported to be more likely than whites to have
AD and other dementias (Alzheimer’s Association, 2009). However, most analyses that
examined racial differences in AD and other dementias, and have simultaneously looked
at age, gender, years of education and co-morbid conditions, report significant differences
on the basis of race do not persist, but are likely related to environmental factors
(Fillenbaum et al, 1998; Fitzpatrick et al, 2004; Fitzpatrick, Dulberg, Kuller, & Jackson,
2006; Kukull et al, 2002; Gurland et al, 1999; Shadlen, Siscovick, Plassman et al., 2007).
In 2000, there were an estimated 411,000 new cases of AD (Alzheimer’s Association, 2009). By 2010, that number is expected to increase to 454,000 new cases per year; by 2029, to 615,000; and by 2050, to 959,000 (Herbert, Beckett, Scherr, & Evans, 2001). By 2050, the number of individuals aged 65 and older with AD is projected to number between 11 million and 16 million—unless medical breakthroughs identify ways to prevent or more effectively treat the disease (Alzheimer’s Association, 2009). Without such developments, by that date, more than 60 percent of people with AD will be aged 85 or older (Hebert, Scherr, Bienias, Bennett & Evans, 2003).

**Diagnostic Testing**

The National Institute of Aging suggests having an early diagnosis and starting treatment in the early stages of AD can help preserve functioning abilities from months to years, even though the underlying AD process cannot be changed (2009). “When diagnosis of dementia occurs earlier in the disease process, more time is available for treatment aimed at maintaining patient function and delaying decline, and for family education about the disease and its management” (Teel, 2004, p.422). Early diagnosis allows for patients and their families to make living arrangements, take care of financial and legal matters (before the individual progresses and legality issues make matters more challenging), and allows for the patient and family to develop support networks to connect with community resources (Alzheimer’s Association, 2009). Additionally, once an individual is diagnosed pharmaceutical treatment can begin to slow development of
plaques and tangles that cause cognitive decline. While drugs such as Aricept and Namenda slow cognitive decline and keep individuals higher functioning for longer periods of time, they do not reverse the effects of the disease in the brain and an individual will continue to decline for the remainder of their life (Alzheimer’s Association, 2009).

Many types of doctors can diagnose and assist in the treatment of dementia. Many times, AD and related memory loss disorders can be diagnosed by the patient’s primary care physician or a referral may be made to have the patient see a neurologist, psychologist, or psychiatrist for diagnosis. A diagnosis of ‘probable AD’ is accurate 80-90% of the time. After completing lab work, doctors can almost always determine that a person has probable dementia, but it may sometimes be difficult to identify the exact type or differential diagnosis (Alzheimer’s Association, 2009).

There are many types of tests that may be used to determine if there is a memory loss disorder: these include physical exams and diagnostic tests, neuropsychological tests (memory tests such as the Mini Mental State Exam) and brain scans (MRI, CT, and PET). There is no single test that proves a person has AD or another form of dementia. The medical workup is designed to evaluate overall health and identify any conditions that could affect how well the mind works. The different tests can help differentiate the 40-50 different types of dementia that have been identified (Alzheimer’s Association, 2009).

The lab work and physical exam is an essential component of the diagnosis process, as it is important for a physician to determine the cause of memory loss or other
symptoms. Some dementia-like symptoms can be reversed if they are caused by treatable conditions such as depression, drug interaction, thyroid problems, excess use of alcohol or certain vitamin deficiencies. Lab work and physical exams typically consist of the doctor asking questions about symptoms experienced, reviewing medical history and medications, and taking blood and urine samples. Often times the caregiver who may accompany the individual to the doctor’s appointment plays a huge role in diagnosis as they are able to better explain symptom severity and frequency (Alzheimer’s Association, 2009).

The mini-mental state examination (MMSE) is one of the neuropsychological tests most commonly used to assess mental function. In the MMSE, an individual asks a patient a series of questions designed to test a range of everyday mental skills. Questions consist of asking the patient to state the current season or month, spell words like “world” backwards, and copying a picture of two interlocking states. The maximum MMSE score is 30 points. A score of 20 - 24 suggests mild dementia, 13 - 20 suggests moderate dementia, and less than 12 indicates severe dementia. The average MMSE score of a person with AD declines about 2 - 4 points each year (Alzheimer’s Association, 2009).

Another popular mental status test is the “mini-cog,” which involves two tasks: remembering and a few minutes later repeating the names of three common objects, and drawing a face of a clock showing all 12 numbers in the right places and a time specified by the examiner. While the mini-cog is only sometimes used by physicians and other healthcare professionals, it is a common tool that family members use due to its easier
application to help them identify if the individual with suspected dementia should be pursuing the diagnosis process (Alzheimer’s Association, 2009).

Neuropsychological tests have been heavily criticized over the last few years related to new findings that show individuals with AD who are able to score perfect cognitive functioning with MMSE scores of 30, and individuals being able to recognize test questions from repeat testing of neuropsychological tests and often times opting out to participate in the diagnostic tests for fear of diagnosis (Shiroky, Schipper, Bergman & Chertkow, 2007).

However, developments of new diagnostic tools have shown promising efforts towards earlier diagnosis for individuals with dementia. Dr. Douglas Scharre of the Ohio State University’s Memory Disorders Research Center has recently developed a new assessment cognitive screening instrument to identify Mild Cognitive Impairment (MCI) and early dementia. The self-administrated test takes an average time of 10 to 15 minutes to complete the test, and is out of a total possible 22 points. These four interchangeable tests help identify individuals with mild thinking and memory impairments at an early stage. The research shows four out of five people (80 percent) with mild thinking cognitive issues will be detected by this test, and 95% of people who are normal thinking will have normal SAGE scores (OSU College of Medicine Department of Neurology, 2010).

Neurological exams and brain imaging tests are also commonly used to assist in the diagnosis of dementia. It is common during this test for a physician or healthcare
professional to examine the patient’s reflexes, coordination and balance, muscle tone and strength, eye movement, speech, and sensation. Declines in these different functioning abilities are often related to the onset of dementia (Alzheimer’s Association, 2009).

New imaging technologies have revolutionized the ability to identify dementias within the brain during diagnosis. Structural imaging provides information about the shape, position or volume of brain tissue. Structural techniques include magnetic resonance imaging (MRI) and computed tomography (CT). Functional imaging reveals how well cells in various brain regions are working by showing how actively the cells use sugar or oxygen. Functional techniques include positron emission tomography (PET) and functional MRI (fMRI). Currently, a standard workup for AD often includes a physical exam with lab tests, a neuropsychological test such as the MMSE, and structural imaging with a MRI. It is also common for an individual to begin testing with their primary care physician and then receive a referral to a specialist, which is most often a neurologist (Alzheimer’s Association, 2009). However, while this combination of diagnostic tests is fairly common, the diagnosing physician will determine what types of tests are needed on an individual basis (Mayo Clinic, 2009).

**Delays in Diagnosis**

There is a considerable amount of evidence recognizing that during diagnosis, physicians, caregivers, the patient, and other family members can contribute to a delay in diagnosis: in one example, Boise et al., 1999 found the mean time between symptom
recognition and diagnosis was 29.7 months, with 19.1 months being the time it took for families to pursue physician consultation. In another study, the delay was as long as 7 years between noticing symptoms, problem recognition, and physician consultation (Clark et al., 2005).

Families often encounter barriers when seeking a diagnosis including the time-consuming and expensive nature of the process, a lack of knowledge regarding available assistance, the patient’s reluctance to see a doctor, and a lack of consensus among family members about how to proceed (Boise et al., 1999). Caregivers can also delay diagnosis of a family member. A lack of understanding about the disease and testing, or from feeling overwhelmed about how to assistance someone through the diagnostic process, as well as many family members fear the expense of testing can develop barriers for a person suspected of memory impairment to receive a diagnosis. Adams (2006) found that many family members when asked about their experience with the diagnostic process “mentioned that they ignored signs too long, or expressed some guilt that they hadn’t done something sooner and many of the spouses or daughters recalled a single traumatic event that had tipped the balance gotten them to seek help” (p.7). Crises and changes to personality and personal interests are the most common reason caregivers become aware of symptoms and pursue physician consultation (Wackerbarth & Johnson, 2002; Adams, 2006; Derouesne et al. 2005; Samuelsson, Annerstedt, Elmstahl, Samuelsson & Grafstroem, 2001).

On top of dementia testing being an extensive process, between one-third and two-thirds of practitioners reported difficulty disclosing the diagnosis to the person with
dementia, which can add additional delays to diagnosis and starting treatment (Bamford, et al., 2004). Beisecker, Chrisman, and Wright found physicians reported feeling inexperienced in dealing with diagnosis uncertainty, which further led to delayed diagnosis (1997). Physicians may be in experienced or feel uncomfortable having to make a diagnosis, many times they also question who to include in the telling of the diagnosis, additionally not having enough time to give a comprehensive assessment or to answer family questions, and not wanting to pursue diagnosis due to patient’s advanced age can all compound the delay to an individual receiving a dementia diagnosis (Boise, Camicioli, Morgan, Rose & Congleton, 1999; Boise et al., 1999; National Institute of Health, 2009).

Over the last few years, there has been a major push for all doctors to be trained in diagnosing dementia. In 2007, the Association of American Medical Colleges (AMC) announced recommendations for geriatric competencies that should be required of all graduating medical students from American medical colleges. One particular request was that students be required to demonstrate competency in distinguishing among the clinical presentations of delirium, dementia, and depression—something many medical school program do not require (Association of American Medical Colleges, 2008).

**Disclosing the Diagnosis**

The majority of research on the subject of dementia diagnosis focuses on physician’s decisions on how and when to disclose diagnosis and to whom the diagnosis would be given (Bamford et al., 2004; Johnson, Bouman, & Pinner, 2000; Kissel &
Carpenter, 2007). Diagnosis disclosure has been cited as one of the most difficult aspects of dementia care by physicians and nurses (Bamford et al., 2004). Additional concerns for care providers include the risk of causing emotional distress, the stigma associated with the diagnostic label, uncertainties about the ability of the person to understand and retain diagnosis; and the lack of a cure or effective treatment for dementia. Cody, Beck, Shue & Pope (2002) found that even among physicians who do report to disclose memory loss disorders, there is little consensus with respect to the pragmatics of the disclosure conversation, such as when to reveal diagnosis, who should communicate it, and who should receive it. While evidence exists regarding diagnostic disclosure in dementia is both inconsistent and limited with the perspectives of people with dementia being largely neglected (Bamford et al., 2004.)

While many physicians agree that a specific diagnosis can increase certainty about treatment options and assist in planning for future care (Foster, 2001), there are still many doctors who are hesitant to disclose a dementia diagnosis (Johnson et al., 2000). However, studies have shown disclosure to an individual with dementia does not prompt a catastrophic emotional event in most people, even those who are only mildly impaired, and may provide some relief once an explanation for symptom is known and a treatment plan is developed (Carpenter et al., 2008). Still, many practitioners agree disclosing diagnosis is important, although diagnosis is not always disclosed or done in a consistent manner.
Guidelines state that doctors should reveal the diagnosis to the caregiver and to the person with dementia; although, some caregivers may not wish for the diagnosis to be disclosed to the person with dementia (Alzheimer’s Association, 2009; Fahy, Wald, Walker, & Livingston, 2003). Research has shown physicians are much more likely to only tell the family the diagnosis rather than include the person with dementia (Cody et al., 2002; Laakkonen et al., 2008). It is much more common for primary care physicians’ verbal participation to be highest during the visit, followed by caregivers and then patients (Schmidt, Lingler & Schulz, 2009). Caregiver satisfaction with interpersonal treatment by the physician was positively related to caregiver’s own verbal participation. Schmidt, Lingler & Schulz suggest by encouraging verbal participation by patients and their caregivers may increase the patient’s active role and caregiver satisfaction with primary care visits. Throughout the diagnosis and following, families and healthcare providers need to be “partners in planning dementia care provided that they communicate effectively about their experiences and approaches to care in a climate that encourages participation and cooperation” (Pashby, Hann & Sunico, 2009, p.837).

**Dementia Caregivers**

Caregivers are individuals who take care of other adults, often parents or spouses (Medline Plus, 2010). Once diagnosed, individuals with AD and related dementias often need assistance with many components of their daily living activities (Alzheimer’s Association, 2009). Although there is not one event that defines the beginning of dementia caregiving, it is often begun prior to diagnosis. Often times, these caregivers
are family members or close friends to the individual that has been diagnosed with the disease (Alzheimer’s Association, 2009). In a study conducted by the Robert Wood Johnson Foundation, 90% of caregivers responded that they felt it was their responsibility to be the caregiver (2009).

Although there is an extensive literature on dementia caregiving, research on family members’ adjustment to the onset of dementia and on the early stage of caregiving is limited. In research studies focusing on the caregivers’ transition into their new role of caregiving, family members reported taking on many new responsibilities in a highly interactive caregiving process consisting primarily of decision-making and supervision. Often times, families are ambivalent about seeking or accepting help from others and seemed to want to maintain the status quo as long as possible. Research has recognized the need for social workers to meet with families in the context of disclosure of a dementia diagnosis or the early adjustment period may help by identifying their losses, normalizing negative feelings, and helping families envision ways they could use outside help (Adams, 2006).

Most Americans will be informal caregivers at some point during their lives. During any given year, there are more than 44 million Americans (21% of the adult population) who provide unpaid care to an elderly or disabled person 18 years or older (U.S. Department of Health and Human Services, 2008). Altogether, informal caregivers provide 80 percent of the long-term care in the United States.

Almost 11 million Americans provide unpaid care for a person with AD or another dementia (Alzheimer’s Association, 2010). The number of caregivers by state
ranges from about 16,000 to 1.2 million depending on the population. With some individuals that have AD, some have more than one unpaid caregiver, for example, people who live with their primary caregiver and receive help from another relative or friend (Mathew Greenwald and Associates, 2009)

In 2009, the 11 million families and other unpaid caregivers of people with AD and other dementias provided an estimated 12.5 billion hours of care. This number represents an average of 21.9 hours of care per caregiver per week, or 1,139 hours of care per caregiver per year. The estimated economic value of the care provided by family and other unpaid caregivers of people with AD and other dementias was $144 billion. This number represents 12.5 billion hours of care valued at $11.50 per hour (Alzheimer’s Association, 2010).

About 60 percent of family and other unpaid caregivers of people with AD and other dementias are women (Mathew Greenwald & Associates, 2009; Minnesota Department of Health, 2008). The 2009 National Alliance for Caregiving (NAC)/AARP survey on caregiving in the United States found that 94 percent of caregivers of people with AD and other dementias were taking care of a relative, including a parent or parent-in-law (62 percent), or even a grandparent.

Caregiving has been identified by the beginning of assistance with at least one activity of daily living (Gaugler et al., 2003). Caregivers of people with AD and other dementias provide more hours of help, on average, than caregivers of other older people. The 2009 NAC/AARP survey on caregiving in the United States found that 15 percent of caregivers of people with AD and other dementias provided more than 40 hours of care a
week, compared with 10 percent of caregivers of other older people (Mathew Greenwald & Associates, 2009). These unpaid caregivers are primarily family members but also include friends.

As the disease progresses and it becomes more challenging for the individual with dementia to remain independent of the care, the average number of hours of unpaid care provided for people with AD and other dementias increases (Zhu et al., 2006). The number of hours of unpaid care is also greater, on average, for people with coexisting medical conditions in addition to AD or another dementia (Zhu et al., 2006). Some family and other unpaid caregivers who live with a person who has AD or other dementia provide supervision and assistance 24 hours a day, 7 days a week, including getting up with the person at night and assisting with all daily activities (Mathew Greenwald and Associates, 2009; Mahoney et al., 2003; Schulz, 2003). Such around-the-clock care is needed when the person cannot be left alone because of risk of wandering or searching, getting lost and other unsafe activities.

Family and other unpaid caregivers of people with AD and other dementias are more likely than caregivers of other older people to assist with activities of daily living (ADLs). Findings from the 2009 NAC/AARP survey on caregiving in the United States show that 38 percent of caregivers of people with Alzheimer’s and other dementias were assisting with three or more ADLs, compared with 27 percent of caregivers of other older people who are also being assisted by caregivers (Mathew Greenwald & Associates, 2009). Just over 31 percent of AD and dementia caregivers manage incontinence and diapers compared with 16 percent of other caregivers. Likewise, 31 percent of AD and
dementia caregivers handle feeding compared with 14 percent of other caregivers (Mathew Greenwald & Associates, 2009).

In addition to activities of daily living, caregivers of people with AD and other dementias are more likely than caregivers of other older people to arrange and supervise services from an agency—46 percent versus 33 percent, respectively (Mathew Greenwald & Associates, 2009). Caregivers of people with AD and other dementias are also more likely to advocate for the person with government agencies and service providers (64 percent of caregivers of people with AD and other dementias versus 50 percent of caregivers of other older people.)

When a person with AD or another dementia moves to an assisted living facility or nursing home, the kinds of help provided by his or her family and other unpaid caregivers usually change, but many caregivers continue to assist with financial and legal affairs and arrangements for medical care and to provide emotional support. Some also continue to help with bathing, dressing and other activities of daily living (Gariety, 2006; Port et al., 2005; Schultz et al., 2006).

**Caregiver Stress and Grief**

There is a growing and often unwieldy body of research looking into the burden experienced by people caring for a person with dementia (Helmes, Green & Almeida, 2005). Even still, there is little consensus on the reasons for the wide variability in the experience of caregiving for a person with dementia. Taking care of a person suffering from dementia is a challenging task in both psychological and physical aspects.
Elderly spousal caregivers are particularly at risk for increased psychiatric morbidity and mortality (Schulz & Beach, 1999). Several theories and models of stress have been used to investigate the negative consequences of caregiving for persons with dementia. A basic principle of this stress is the assumption that an emotional event does not automatically provoke stress; several factors compound this relationship (Pearlin, Mullan, Semple, & Skaff, 1990).

“Caring for an elder takes a special kind of person and exacts an enormous toll upon the caregiver. It is unpredictable: the elder’s health could change at any minute, requiring a trip to the doctor, the hospital, or the emergency room. And, caregivers overwhelmingly say the emotional toll is the worst—watching their parent’s or other relative’s health and mental acuity decline” (Brown, 2005, p.11). Family caregivers are vital in providing informal care to these individuals who are diagnosed. While caregivers provide invaluable services to family members with dementia, the stress of caregiving can challenge their physical, social, and emotional well-being (Pinquart & Sorensen, 2003; Son, Erno, Shea, Femia, Zarit & Stephens, 2007; Vitaliano, Zhang & Scanlon, 2003).

It is widely recognized that the challenges of caring for a family member with dementia can result in high levels of stress and psychological morbidity (Morris et al., 1988; Schultz et al., 1990). Developing a strong understanding of the factors that determine caregiver’s stress is a major priority as high levels of stress have been linked to increased use of primary care and respite services and earlier admittance to long-term or institutional care (Brown et al., 1990).
Although most caregivers are in good health, it is not uncommon for caregivers to have serious health problems. Research shows that caregivers are more likely to be have symptoms of depression or anxiety; are more likely to have a long-term medical problem, such as heart disease, cancer, diabetes, or arthritis; have higher levels of stress hormones; spend more days sick with an infectious disease; have a weaker immune response to the influenza, or flu, vaccine; have slower wound healing; have higher levels of obesity; and may be at higher risk for mental decline, including problems with memory and paying attention (U.S. Department of Health and Human Services, 2008).

In studies that examine caregivers’ emotional experiences with caring for a family member with dementia, caregivers’ subjective grief was initially high following diagnosis, tended to declining during the middle stages of caregiving, and then to increase later at the terminal stage of the illness (Adams & Sanders, 2004). Caregivers’ level of grief has been shown to be related to their depressive symptoms (Sanders & Adams, 2005). Issues precipitating grieving included initial diagnosis (Diwan, Hougham, & Sachs, 2009).

Caring for a person with AD or another dementia is often very difficult, and many family and other unpaid caregivers experience high levels of emotional stress and depression as a result. Caregiving also has a negative impact on the health, employment, income and financial security of many caregivers (Alzheimer’s Association, 2010).

Addressing caregiver stress and burden has been done using interventions that provide breaks to caregivers (Sussman & Regehr, 2006) through respite activities as well
as informational/educational programs which explain what the disease is, the progression, and the potential needs of an individual who has been diagnosed with dementia. Reducing caregiver burden has been one method of measuring effectiveness of support services for families of a person diagnosed with dementia.

**Types of Support Services**

Caregiver support services are community-based activities designed to alleviate stress and promote competencies and behaviors that will increase the ability of families to successfully provide care, enable families to use other resources and opportunities available in the community, and create supportive networks to enhance caregiving for a person with dementia (U.S. Department of Health and Human Services, 2010). There are respite programs which allow for families to have breaks, and educational and psychosocial needs of the caregiver to be able to provide care for an individual with dementia.

There are many different types of programs that provide respite and assistance to caregivers in providing care while the individual is still living within the home. Caregivers and individuals with dementia both need a break from daily routines. Respite care assists by providing a new environment or time to relax. It can be for a few hours or several days or weeks, depending on needs and interests. Respite care can be provided at home, at an adult day center or in a care setting. Home and community-based services,
which are a type of respite, can include companion services, home health services, and adult day care.

Companion or sitter services refer to services, which involve individuals coming to the home to help the caregiver and the person with dementia. These can include supervision services which help with “sitting”, recreational activities or visiting; personal care services which usually consist of assistance with bathing, dressing, toileting, exercising or other personal care activities; and services which are often housekeeping, shopping or meal preparation assistance (Alzheimer’s Association, 2009).

Home care consists of a professional coming into the home to provide care to an individual. Some home care can only be given by licensed health workers, such as skilled nursing care, rehabilitation or other in-home services for the treatment of an illness or injury. Medicare may pay for some home health care, but only if the individual meets certain qualifications and conditions (Alzheimer’s Association, 2009).

An adult day health care another type of home and community based care service that is available to caregivers. These adult day centers provide care outside the home and are designed to meet individual needs while supporting strengths, abilities and independence. Participants who attend adult day care have the opportunity to interact with others while being part of a structured environment (Alzheimer’s Association 2010).

Another type of support service that is available to caregivers and families is residential care. If the person with dementia prefers a community living environment or if home care is no longer possible, then often an individual will go into a residential care
building or facility. These types of care programs include independent living for seniors, adult group homes, assisted living facilities, continuing care retirement communities, and nursing homes (Alzheimer’s Association, 2009).

Independent living for seniors is usually in a small, easy-to-maintain private apartment or house within a community of seniors. It is common for these buildings to be entirely composed of individuals over the age of 55 or 60, and is considered to be the least-restricting environment both in terms of seniors having privacy and their own personal responsibilities (Alzheimer’s Association, 2009).

Adult group homes, also known as board and care homes, adult foster care, elder care homes, or residential care homes can provide meals and help with some daily activities (such as money management, scheduling transportation, reminders to take medication, laundry and housekeeping). These homes are well-known to serve for the severely disabled, but they are also commonly used for individuals with dementia who lack social support to be able to live independently within the community, but also are not an intermediate level of care for a living environment such as that of a nursing home (Alzheimer’s Association, 2009)

Assisted living residences generally provide 24-hour staff, recreational activities, meals, housekeeping, laundry and transportation. Definitions of assisted living and the specific regulations differ from state to state. Residents may choose which services they receive from the residence such as house cleaning assistance, help with grooming or medication reminders (Alzheimer’s Association, 2009).
Nursing homes may provide a full range of care needs, including acute care and long-term care. Acute care rehabilitation is short-term care offered for people with injuries; illnesses or post-operative care needs that will eventually be able to recover outside a hospital. Long-term care is provided to individuals who require longer stays (Alzheimer’s Association, 2009).

Additionally, an individual with dementia may receive hospice care. Hospice care is provided to individuals who are terminally ill in their homes or in a care setting, generally with an expected survival of six months or less. Care may consist of end-of-life planning, palliative (pain) management, and bereavement for family members following the death of an AD patient (Alzheimer’s Association, 2009).

The other types of support services address the need for caregivers to understand how to assist in the care of a person with dementia. Support groups, counseling, and other types of caregiver support services, have shown to be helpful in reducing caregiver stress and enhancing coping skills. These services can be protective factors for the caregivers, and promotes the identification and utilization of peer relationships (Wilks & Croom, 2008).

There are also programs which can assist in educating caregivers about the disease. Education programs are helpful in supporting caregivers to feel more confident in their new roles as caregiver (Roberts & Silverio 2009). Additionally, there are many types of psychoeducational models to teach caregivers strategies to deal with challenging behaviors that accompany AD and related dementias (Gerdner, Buckwalter & Reed,
These models enhance caregivers’ understanding of how to provide adaption to daily living needs of individuals with the disease.

For the purposes of this paper, effectiveness of programs is recognized by numbers associated with utilization, and effectiveness in providing support to the needs of caregivers. Utilization of services will be discussed later, but there are many research studies which support the effectiveness of support programs in reducing stress and burden associated with family members caring for a person with dementia. Caregivers are needed to provide care for a family member with dementia to help keep healthcare costs down and family members out of long-term care as long as possible (Brown, 2005), but caregivers need assistance to be able to take care of themselves to maintain their role as dementia caregiver (Alzheimer’s Association, 2010).

Support programs such as adult day care and homemaker services have been found to be effective in assisting in reducing early institutionalization as well as: restructuring caregiving time, providing respite to family members, creating an understanding and knowledge of symptoms and needs of care recipient, increasing life satisfaction for caregivers and subjective well-being, and reducing caregiver stress, depression and burden (Gaugler et al., 2002; Kaufman, Kosberg, Leeper & Tang, 2009; Mossello et al., 2008; Piquart & Sorensen, 2006; Sussman & Regehr, 2009; Townsend & Kosloski, 2002). It should also be noted multi-component interventions had the largest success in reducing the risk for institutionalization (Piquart & Sorensen, 2006). Additionally, psychoeducational interventions that require active participation of
caregivers had the broadest effects in caregiver understanding of patients symptoms and care needs (Piquart & Sorensen, 2006).

While caregiver support services are provided by a broad range of public, not-for-profit, and private service providers, major service gaps exist in areas such as culturally appropriate services; transportation; emergency, overnight, and weekend respite; financial assistance; and care in rural areas. Overcoming these service gaps and establishing a comprehensive caregiver service network will require collaboration and coordination among formal and informal networks, public and private entities, and local and state systems (Whittier, Scharlach & Dal Santo, 2005). Currently these gaps in the system do limit the availability of such programs, and particularly in areas for families struggling with financial hardship availability of support services can be difficult to manage due to the high cost of care (Alzheimer’s Association, 2010).

**Caregiver Utilization of Services**

While many caregivers feel they have an understanding of AD and dementia at diagnosis, many of them feel they need additional support on what to do following diagnosis. Caregivers can be left wondering what needs to be done or how to plan for care of the individual with dementia (Adams, 2005; Laakkonen et al., 2008). Caregivers often feel this information would come from the patient’s physician (Ploeg et al., 2009), when often times it does not (Laakkonen et al., 2008).
In such cases where caregiver stress is high, support services become essential for families (Sussman & Regehr, 2009). In a study looking at what services were most needed as caregivers reported, respite and counseling topped the list (Alwin, Oberg, & Krevers, 2009; Parker, Mills & Abbey, 2008). Despite some caregivers wanting and many needing support services, caregivers are often unsure of the availability of such services and the way to connect with providers (Adams, 2005). In Adams’s study, many participants were ambivalent about seeking or accepting help from others and seemed to want to maintain the status quo as long as possible (2005).

There are many problems associated with how families connect to available support services. Adams found that a majority of their study’s participants expressed either disinterest in or actual avoidance of help-seeking, even though they admitted to feelings of distress and being overtaxed by the needs of their loved one (2005). Additionally, some studies report just a general lack of knowledge regarding what services are available or why they could be beneficial to caring for an individual (Fortinsky, Kulldorff, Kleppinger & Kenyon-Pesce, 2009; Laakkonen et al., 2008; Ploeg et al., 2009). While often misunderstood by the caregiver, utilizing services has been found to be both beneficial to the person with dementia and their family, and can often delay institutionalization (Gaugler, Kane, Kane & Newcomer, 2005). A 2005 found that many of participating caregivers were not using support services, mainly because of perceived lack of need or lack of awareness (Broadaty, Thomson, Thompson & Fine, 2005). Better public promotion of services, destigmatising dementia, more affordable support service programs, and encouraging referrals from health professional could help
overcome the barriers to service use.

Finding numbers that represent the utilization rates of support services are very difficult to obtain. Most often, utilization rates are reported annually through total cost of insurance reimbursement and healthcare expenditures. In 2004, one-quarter of Medicare beneficiaries aged 65 and older who received Medicare-covered home health care services were people with AD and other dementias (Wolff, 2008), about twice as many as one would expect given the proportion of Medicare beneficiaries with AD and other dementias among all Medicare beneficiaries. People with AD and other dementias make up a large proportion of all elderly people who receive non-medical home care, adult day center services, assisted living and nursing home care (Alzheimer’s Association, 2010). In the United States, there are more than one-third of older people who received primarily non-medical home care services, such as personal care and homemaker services (Fortinsky, Fenster & Judge, 2004; Hirdes et al., 2004; Mitchell, Salmon, Polivka & Soberon-Ferrer, 2006). In 2009, the average hourly rate for non-medical home care, including personal care and homemaker services, was $19 or $152 for an eight-hour day (MetLife Mature Market Institute, 2009).

At least half of elderly adult day center participants have AD or other dementia (Partners in Caregiving, 2002; O’Keeffe & Siebenaler, 2006). In 2009, the average cost of adult day services was $67 a day (MetLife Mature Market Institute, 2009). Ninety-five percent of adult day centers provided care for people with AD and other dementias, and 2 percent of these centers charged an additional fee for these clients.
Estimates from various studies indicate that 45–67 percent of residents of assisted living facilities have AD or other dementia (Bynum, 2009; Hyde, Perez & Forester, 2007). In 2009, the average cost for basic services in an assisted living facility was $3,131 a month, or $37,572 a year (MetLife Mature Market Institute, 2009). Fifty-nine percent of assisted living facilities provided specialized AD and dementia care, and charged an average of $4,435 a month, or $53,220 a year, for this care.

In 2008, 68 percent of all nursing home residents had some degree of cognitive impairment, including 27 percent who had mild cognitive impairment and 41 percent who had moderate to severe cognitive impairment (Centers for Medicare and Medicaid Services, 2009). In June 2009, 47 percent of all nursing home residents had a diagnosis of AD or other dementia in their nursing home record (American Health Care Association, 2009). In 2009, the average cost for a private room in a nursing home was $219 a day, or $79,935 a year. The average cost of a semi-private room in a nursing home was $198 a day, or $72,270 a year (MetLife Mature Market Institute, 2009). Twenty-nine percent of nursing homes had separate AD special care units. The average cost for a private room in an AD special care unit was $233 a day, or $85,045 a year, and the average cost for a semi-private room was $208 a day, or $75,920 a year (MetLife Mature Market Institute, 2009).
Advanced Care Planning

Once a loved one has been diagnosed with dementia, family members often reported taking on many new responsibilities in a highly interactive caregiving process consisting primarily of decision-making and supervision (Adams, 2005). Many participants reported experiencing frustration, resentment, grief, and relational deprivation along with increased protectiveness and tenderness towards the person with dementia. Caregivers often recount a highly negative emotional response to disclosure, whereas many physicians reported that families handled the information well (Connell, Boise, Stuckey, Holmes & Hudson, 2004). Caregivers have expressed a range of preferences for how the diagnosis should have been disclosed, from a direct approach to having the physician ease them in to the results. Implications from this study concluded physicians should consult with the patient and family at the outset of the diagnostic process to better understand their preferences for diagnostic disclosure.

Ducharme et al developed a proactive psychoeducational intervention program for AD family caregivers following diagnostic disclosure (2009). Based on a theoretical model of role transitions and a participatory approach, the study comprised four steps: (a) exploring caregiver needs; (b) developing and validating a program proposal based on caregiver expressed needs; (c) formalizing program through intervention mapping; and (d) testing and qualitatively evaluating the program. The psychoeducational program consisted of seven individual sessions aimed at fostering knowledge and skills required to ensure successful transition to the caregiver role. The authors noted that intervention
mapping in particular allowed for the opportunity to integrate theoretical and empirical elements in a formal intervention model.

While many caregivers are interested in received advanced care planning assistance, they do not receive it. Following disclosure of diagnosis, Lakkonen et al surveyed a large proportion of caregivers who felt they had a need for discussion about advanced care planning with their physician (2008). Caregivers wanted more information from physicians about expected progress of the disease, financial and legal issues, available services, research projects and their own personal needs (Beisecker, Chrisman & Wright, 1997; Vernooij-Dassen, Derksen, Scheltens & Moniz-Cook, 2006). Nursing interventions have been suggested to include encouraging caregivers to learn more about the disease understand what is available in the community for social support and understand legal and financial issues following diagnosis (Skinner, 2009).

**Alternative Diagnostic Process**

Results of another diagnosis study indicate that more could be done during the diagnostic process to help caregivers understand the dementia and to learn about and connect with available community support. Models of care that focus on more comprehensive services at the time of diagnosis may yield better outcomes for family dementia caregivers, particularly in connecting them with information and support to care for someone with the disease (Derksen, Vernooij-Dassen, Scheltens, & Olde-Rikkert, 2005).
In the Netherlands, a model has been developed to enhance the diagnostic process which consists of the use of an interdisciplinary team offering multiple levels of information and support (Derksen et al, 2005). During this phase of the diagnostic process, it allows for patients and families to receive further explanation where the doctor has an opportunity to discuss the diagnosis. The physician is able to give additional information about test results and connect the information to the cognitive problems of the patient with dementia. During the meeting time, there may also be an opportunity to discuss challenging issues regarding the individual’s independence. One major question that often comes up following diagnosis is whether or not the individual should continue driving or should be living alone. This would allow caregivers the opportunity to ask the doctor questions.

Part of the diagnostic process in the Netherlands also involves the nurse planning a meeting with the caregiver, in which the caregivers’ sense of competence and the reactions of the person with dementia are discussed. Together with the information about the person with dementia and the caregiver’s perceptions of the disclosure, it gives the nurse a starting point for the needs assessment (Derksen et al, 2005). There could be additional opportunities for social workers to meet with families as part of the final stage of the diagnostic process to develop an advanced care plan or to set the family up with information.

An additional consideration comes from “the rule of three”. Wald, Fahy, Walker and Livingston suggest that it takes closer to three visits before a caregiver is ready to
talk about themselves and what support they need as a caregiver (2003). Caregivers typically focused on practical and concrete issues surrounding the patient they were caring for during the first two visits. Caregivers reported not wanting to be given too much information at once as they found it overwhelming, but wanted the information in smaller dissections throughout the timeframe of a year (Wald et al., 2003).

One of the most interesting suggestions for interventions involving collaboration between Alzheimer’s Association chapters and primary care physicians came from a model developed by Fortinsky et al., 2009).

“In the intervention group, dementia care consultants located at an Alzheimer’s association chapter provided individualized counseling and support over a 12-month period, and sent copies of care plans developed with family caregivers to referring primary care physicians. In the control group, family caregivers received educational and community resource information but no care consultation. Nursing home admission of patients during the 12-month study period was the primary outcome; secondary outcomes included measures of caregiver self-efficacy for managing dementia, caregiver depressive symptoms, and caregiver burden” (p. 162).

The dementia care consultation intervention showed favorable effects on nursing home admission and on caregiver outcomes among intervention group caregivers more satisfied with the intervention, but there were many communication challenges that came with the association attempting to collaborate with the primary care physicians making diagnoses. These often included keeping all involved parties up to date with appropriate service information, and while caregivers were commonly referred to the association for services, they often did not understand what the services were or how the services would be beneficial to their situation.
Diagnosing AD and other dementias can be a difficult and time-consuming process, and individuals and families may experience delays in dementia diagnosis due to the complex testing processes, and a lack of understanding within the community about the needs of families during the diagnostic process. It has been suggested that making a diagnosis of dementia is not just a medical process, but also a social act which removes the person with the disease and the caregiver to a new social group that is highly stigmatized (Husband, 1999). Family and individual needs’ for understanding the disease and how to provide care for a dementia patient, and how they obtain such information is unclear and under-researched. As such, little is known regarding the needs of individuals with dementia and their caregivers following diagnosis and what can be done to enhance the diagnostic experience for families faced with an overwhelming and difficult diagnosis.

**Purpose of Study**

Dementia has been described as the modern epidemic of later life and is the most feared diagnosis by older adults (Bond & Corner, 2001). Additionally, diagnosis disclosure has been cited as one of the five most difficult aspects of dementia care by physicians and nurses (Bamford et al., 2004). Some studies have reported a range of negative emotional reactions to the diagnosis, including anger, anxiety, fear, depression, or despair (Adams, 2006). However, there are many positive consequences of the diagnosis disclosure identified by people with dementia and their caregivers, such as: psychological benefits, improved understanding of the problems associated with
dementia, opportunity for decision making and future planning, and increased access to available treatment and support services (Alzheimer’s Association, 2009).

Unfortunately, to date, there has been little person and caregiver-oriented research to inform the development of evidence-based supportive dementia disclosure practices. Most studies of diagnosis disclosure for dementia have focused on exploring professionals’ attitudes and practices (Bamford et al., 2004). The views, experiences and coping responses of people with dementia and their caregivers remain largely under-researched (Aminzaheh et al., 2007; Adams, 2006).

The purpose of this study was to further understand the experiences of caregivers during the diagnostic process, specifically looking to see whether or not families were experiencing challenges to diagnosis, and to identify what caregivers’ needs were following diagnosis. Additionally, the researchers questioned how caregivers learned about available support services, and how long and why caregivers waited to contact the Alzheimer’s Association following diagnosis.
CHAPTER 3

METHODS

Design

This study utilized a cross-sectional design to understand what needs caregivers had during the diagnostic process of dementia, and to identify how families were supported following diagnosis. A printed and online 25-item questionnaire was developed by the researchers to explore diagnosis and service utilization of families who attend education and support group programs through the Alzheimer’s Association Central Ohio Chapter. This study is based on the 106 caregivers (N=106) who elected to participate.

Sampling

The population for this study consisted of caregivers (e.g. spouses, adult children, etc.) of individuals with either a diagnosis or suspected diagnosis of AD and other related dementias. For the purposes of the current study, a caregiver is someone who has self-identified to provide care or assist with the activities of daily living for an individual with dementia, either at home, in community care, or in an institutional care setting.
Caregivers were asked to participate following attendance at educational and support programs offered through the local chapter of the Alzheimer’s Association of Central Ohio.

Participants were invited to complete a 25-item survey about their experience regarding diagnosis. The written surveys were distributed by researchers at Alzheimer’s Association programs where participants were given the choice to return the survey to researchers before they left the event, or they were given a pre-paid envelope to mail the completed questionnaire back at a later time of their choosing. Caregivers were also contacted via email through the association’s general mailing list about participating in an online version of the survey. Additionally, the web address for the online version of the survey was announced, and handouts with the link were distributed during the education and support programs.

The final sample consisted of 106 (N=106) caregivers from the Central Ohio community (Delaware, Fairfield, Fayette, Franklin, Hocking, Licking, Madison, Marion, Morrow, Perry, Pickaway, Pike, Ross, and Union Counties). Of the 106 respondents, 26 responded using the written questionnaire and 90 selected completing the questionnaire online.
**Instrumentation**

In order to collect this information about the diagnostic experience, caregivers were asked to complete a 25-item survey. This method was chosen due to the low commitment of time needed for respondents to complete the survey, the inexpensive benefit of using questionnaires to collect data, and the anonymity questionnaires provide to participants (Monette, Sullivan & DeJong, 2008). Items included in the questionnaire focused on the following: demographic and contextual variables and characteristics surrounding the diagnosis (e.g., type of diagnosis; details of the diagnostic process; support service knowledge; use community resources; and the caregiving role). The survey questions have been categorized in Table 1.

While the majority of the questionnaire was composed of closed-ended questions, two open-ended questions were included which allowed caregivers to write in their own responses. These questions specifically asked for respondents’ opinions about their experiences during and following the diagnostic process. This type of question is suitable for exploratory studies, as the researchers did not want to limit additional concerns caregivers experienced during the diagnostic process that the close-ended questions might have inadvertently overlooked.
Measures

Measures selected for this study represent characteristics associated with the person with dementia, their caregiver, the diagnostic experience, and caregiver support services which were based on previous literature. Dichotomous and categorical measures were utilized to explore the possible needs of caregivers during and following diagnosis.

Location. Location has been found to be a factor that influences caregivers’ access to available support services, and can impact the utilization families have to educational and respite services (Alzheimer’s Association, 2009). Researchers were interested to see whether support and education resources were available following diagnosis, particularly in rural communities, which historically have experienced shortages in available support services (Teel, 2004). Respondents were asked to fill in their five-digit zip code.

Age of care recipient. Age has been found to be a major predictor in the onset of AD, as age is the biggest risk factor for the disease (Alzheimer’s Association, 2009). This response was left open in which respondents could respond with any number (between one to three digits). Additionally, respondents were asked to give the current age of the care recipient in order for researchers to obtain the length of time the person with dementia and caregiver had been living with the diagnosis.
Table 1
Types of Survey Questions

<table>
<thead>
<tr>
<th>Category</th>
<th>Questions</th>
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<tbody>
<tr>
<td>Demographics</td>
<td>What is your zip code?</td>
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<td></td>
<td>What is the gender of the care recipient?</td>
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<td></td>
<td>What is the race of the care recipient?</td>
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<td></td>
<td>What was the age of care recipient at diagnosis?</td>
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<td></td>
<td>What is the current age of the care recipient?</td>
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<td></td>
<td>What is your relationship to the care recipient?</td>
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<td></td>
<td>What is the current diagnosis for the care recipient regarding their memory loss?</td>
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<tr>
<td>Details of diagnosis process</td>
<td>Who made the current diagnosis?</td>
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<td></td>
<td>Where is the doctor’s office located?</td>
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<td></td>
<td>What kind of diagnostic test(s) was used?</td>
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<td></td>
<td>Did insurance cover the diagnostic test?</td>
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<td></td>
<td>How long did it take to get this diagnosis?</td>
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<td></td>
<td>Were you ever given a different diagnosis for the care recipient regarding their memory loss?</td>
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<td></td>
<td>If yes, what was this other diagnosis?</td>
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<tr>
<td>Caregiving role</td>
<td>Did you suspect the diagnosis for the care recipient before the diagnosis was confirmed?</td>
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<td></td>
<td>At the time of diagnosis, do you feel you were given enough information about the disease and how to care for your loved one?</td>
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<td></td>
<td>One year following the time of diagnosis, do you feel you were given enough information about the disease and how to care for your loved one?</td>
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<tr>
<td>Knowledge of support services</td>
<td>Were you referred to any support programs by the doctor who diagnosed the care recipient?</td>
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<td></td>
<td>At the time of diagnosis, do you feel you were given enough information about community resources to help care for your loved one?</td>
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<tr>
<td></td>
<td>One year following the time of diagnosis, did you feel you were given enough information about community resources to help care for your loved one?</td>
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<td></td>
<td>How long after diagnosis did you first learn about the Alzheimer’s Association?</td>
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<td></td>
<td>How did you first learn about the Alzheimer’s Association?</td>
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<tr>
<td>Use of support services</td>
<td>If you didn’t contact the Alzheimer’s Association after learning about us, what was the reason(s)?</td>
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<td></td>
<td>What programs do you or your care recipient currently use?</td>
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<td></td>
<td>Open-ended responses on diagnostic process</td>
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<td></td>
<td>What would have been helpful to you and your family during the diagnosis process?</td>
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<td></td>
<td>What would have been helpful to you and your family following diagnosis?</td>
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</tbody>
</table>
Gender of care recipient. Gender has been found to be an important factor associated with what the care needs of the person with dementia (Alzheimer’s Association, 2009). This dichotomous variable was coded as 0=male or 1=female.

Race of care recipient. Race has been established to be an important predictor of the diagnostic process, particularly in how quickly an individual is diagnosed with dementia (Clark, Kutner, Goldstein, Peterson-Hazen, Garner, Zhang et al., 2005). The categorical response options for respondents included: White, African American, Hispanic, Asian and an “other” option with the opportunity for the respondent to write in the additional category to identify an unlisted race.

Relationship to the care recipient. The relationship the caregiver has to the person with dementia has been found to be a predictor in the amount and type of support services the caregiver chooses to utilize to assist with dementia care (Ablitt, 2009; Alzheimer’s Association, 2010; Bern-Klug & Forbes-Thompson, 2008). This variable gave respondents the opportunity to select from the following five choices: spouse or partner, adult child, brother or sister, friend, or an “other” option with the opportunity for the respondent to write in the unlisted type of relationship.

Type of dementia diagnosis. The type of dementia diagnosis has been found to be an important factor in determining which type of support services should be utilized in dementia care (Alzheimer’s Association, 2009). Respondents were able to select from the following choices: AD, Lewy Body dementia, vascular dementia, Multi-infract dementia, dementia unspecified, Frontotemporal dementia, no diagnosis, or an “other”
option with the opportunity for the respondent to write in the unlisted type of dementia diagnosis. These options were selected because they were recognized as the most common types of dementia diagnoses (Alzheimer’s Association, 2009).

*Diagnosing professional’s specialization.* The type of professional that confirms the diagnosis of dementia has been found to be an important factor in determining what information individuals and families receive at diagnosis (Alzheimer’s Association, 2009; Bamford et al., 2004). The options for respondents to select as a response included primary care physician/family doctor, neurologist, psychologist, psychiatrist, or an “other” option with the opportunity for the respondent to write in the unlisted care recipient’s diagnosis professional. The categorical variables were selected as such due to these selections being the most common types of diagnosing professionals as recognized by the Alzheimer’s Association (2009).

*Type of diagnostic tests used.* The type of testing that was used to make the dementia diagnosis has been recognized as an important factor in the diagnostic process (Alzheimer’s Association, 2009). Respondents were given three categorical options in selecting diagnostic test procedures that are most often associated with dementia diagnosis: laboratory tests, neuropsychological tests, and brain imaging tests (Alzheimer’s Association, 2009). Respondents were able to select one of the three categories, two of the three, or all three categories. Additionally, respondents also had the option to select unknown if they were not sure what diagnostic tests were performed.
Length of time for diagnosis. The amount of time it takes for the person with dementia and the caregiver to receive a confirmed diagnosis of dementia has been recognized as a predictor of families’ having a positive experience with the diagnostic process (Alzheimer’s Association, 2009; Boise et al., 1999). Respondents were given six categorical options in selecting the length of time diagnosis took for families once diagnosis was being pursued through diagnostic testing. Respondents had the option to select the diagnosis was given on the first visit, within 1-3 months of testing, within 4-6 months of testing, within 7-12 months of testing, between 1-2 years of testing, and finally the option to select that diagnostic testing took over 2 years to confirm a dementia diagnosis.

Caregiver suspected dementia diagnosis. This was an exploratory question the researchers were curious in finding out how many caregivers were expecting or not expecting the diagnosis of dementia, prior to the diagnosis being confirmed by a professional. This dichotomous variable was examining how familiar caregivers were in recognizing the symptoms of dementia (no=0 and yes=1).

Family given a differential diagnosis. Differential diagnoses have been suggested to be a predictor of better quality of life for the person with dementia and leads to a more individualized treatment plan to offset the progression of the disease (Alzheimer’s Association, 2009). Researchers used this dichotomous variable (no=0 and yes=1) to determine how many families experienced a differential diagnosis during the diagnostic
testing process for dementia. Respondents that answered yes were also given an opportunity to explain what the previous diagnosis was prior to the current diagnosis.

**Insurance coverage for diagnostic testing.** This was another exploratory question to determine whether persons with dementia had insurance coverage to pay for their diagnostic testing. With reports of 43.6 million individuals being uninsured in the United States (Center for Disease Control and Prevention, 2009), the researchers hoped this would shed insight into whether or not insurance coverage impacted the diagnostic process. This dichotomous variable was investigating whether or not the diagnostic process was covered by the patient’s insurance (no=0 and yes=1).

**Caregiving role.** Dichotomous variables were also used to identify the needs of individuals as they shifted into the caregiving role following diagnosis, and what potential needs these individuals may have had during a family members diagnostic testing for dementia. Respondents were asked at diagnosis, if they had information about the disease and their role in providing dementia care (no=0 and yes=1), and then respondents were also asked if they had information about the disease and their role in providing dementia care one year following diagnosis (no=0 and yes=1). A number of studies have illustrated that often times individuals and families are not well supported with information following a dementia diagnosis (Laakkonen, 2008; Bamford et al., 2004; Adams, 2006).

**Caregiver knowledge of support services.** Dichotomous variables were also used to identify the caregiver’s knowledge of support services available to them for assistance
with dementia care. Respondents were asked at diagnosis, if they had information about available community resources to assist them with caregiving for a person with dementia (no=0 and yes=1), and then respondents were also asked if they had information about available community resources to assist them with caregiving for a person with dementia one year following diagnosis (no=0 and yes=1). Previous literature has shown obtaining support information and referrals from the professional has been a challenge for many families during the diagnostic process (Ploeg et al., 2009; Laakkonen et al., 2008). There was also a question provided in this section to determine how long after diagnosis did it take for caregivers to learn about the Alzheimer’s Association. Respondents were given seven categorical options in selecting the length of time from diagnosis that a caregiver became informed about the Alzheimer’s Association. Respondents had the option to select between seven categories to describe the timeframe ranging from a referral to the Alzheimer’s Association being made at the visit where the person was diagnosed to caregivers not learning about association until 2 or more years following diagnosis. There was also the opportunity to select that as a caregiver, the respondent was already aware of the Alzheimer’s Association and services prior to diagnosis.

Caregivers informed about Alzheimer’s Association. Respondents were asked 12 categories to select as places where they learned about the Alzheimer’s Association. The first 11 referrals were different types of support services and outlets families could have obtained the information from. There was also an “other” option with the opportunity for the respondent to write in the unlisted method for referral to the Alzheimer’s Association.
Reasons caregiver did not contact association. Respondents were asked reasons behind why they did not contact the Alzheimer’s Association following learning about their organization. Respondents were given 6 categories to select as reasons for whether they had or had not contacted the organization immediately following learning of available services. The questions were related to particular challenges caregivers experience when trying to locate appropriate local resources (Adams, 2006; Broadaty et al., 2005; Fortinsky et al., 2009).

Data Analysis

Quantitative data was entered into and analyzed using SPSS 17.0 software. Following data cleaning, descriptive data was generated to learn more about the sample and the diagnostic process. Caregivers were asked to explain what would have been beneficial during diagnosis, and what would have been beneficial following diagnosis. The two open-ended questions were analyzed using a simple content analysis and through that process illustrative quotes were identified to provide more depth of understanding of quantitative findings of caregivers’ experiences. As this was study was quantitative in nature, the qualitative data was used in an auxiliary way to provide support and context to the quantitative data.
CHAPTER 4

RESULTS

The final sample consisted of 106 caregivers to persons with dementia from the Central Ohio community (N=106). The majority of caregivers were White (90%) and urban dwelling (63%). Almost exactly half of the sample was a male with dementia (49%). The mean age for diagnosis of the care recipient was 77 years of age (M = 77). Individuals were most commonly diagnosed with AD (53%), followed by dementia unspecified (16%), and then vascular dementia (8%). Sample demographic characteristics are summarized in Table 2.

Table 3 displays the outcomes from the diagnostic process. When examining how families received diagnosis, the majority of caregivers reported individuals diagnosed with a form of dementia received their diagnosis from a neurologist (69%), followed by a primary care physician (22%), and other health professionals that included psychologists, psychiatrists, gerontologists, and neuropsychiatrists (9%).

Most individuals diagnosed with AD or another related dementia received all three types of diagnostic tests (57%), however of all the diagnoses, 95% received a neuropsychological test, 77% received a type of brain imaging test, and 67% of persons diagnosed with dementia received a laboratory tests in the determination of the cognitive
impairment. Additionally, 88% of individuals were diagnosed within one year from when they began pursuing a diagnosis.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender of caregiver</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>49.1</td>
</tr>
<tr>
<td>Female</td>
<td>50.0</td>
</tr>
<tr>
<td>Race/ethnicity of caregiver</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>89.6</td>
</tr>
<tr>
<td>African American</td>
<td>9.4</td>
</tr>
<tr>
<td>Asian</td>
<td>0.9</td>
</tr>
<tr>
<td>County where caregiver is located</td>
<td></td>
</tr>
<tr>
<td>Franklin county</td>
<td>63.3</td>
</tr>
<tr>
<td>Outside of Franklin county</td>
<td>37.7</td>
</tr>
<tr>
<td>Relationship to the care recipient</td>
<td></td>
</tr>
<tr>
<td>Spouse or Partner</td>
<td>50.9</td>
</tr>
<tr>
<td>Adult Child</td>
<td>39.6</td>
</tr>
<tr>
<td>Sibling</td>
<td>0.9</td>
</tr>
<tr>
<td>Friend</td>
<td>1.9</td>
</tr>
<tr>
<td>Other</td>
<td>6.6</td>
</tr>
<tr>
<td>Current diagnosis of care recipient</td>
<td></td>
</tr>
<tr>
<td>Alzheimer’s disease</td>
<td>52.9</td>
</tr>
<tr>
<td>Lewy Body dementia</td>
<td>3.8</td>
</tr>
<tr>
<td>Vascular dementia</td>
<td>7.7</td>
</tr>
<tr>
<td>Multi-Infarct dementia</td>
<td>1.9</td>
</tr>
<tr>
<td>Frontotemporal dementia</td>
<td>13.5</td>
</tr>
<tr>
<td>Dementia unspecified</td>
<td>16.3</td>
</tr>
<tr>
<td>No diagnosis</td>
<td>1.9</td>
</tr>
<tr>
<td>Other</td>
<td>1.9</td>
</tr>
</tbody>
</table>

It was not uncommon for caregivers to expect a dementia diagnosis. Nearly 77% of all caregivers surveyed admitted they suspected a dementia diagnosis prior to the physician confirming. Additionally, for 30% of families the diagnosis changed and became a differential diagnosis in that diagnosis became more specified in the type of dementia.
Caregivers were also asked about whether or not the person with dementia’s insurance covered the diagnostic testing associated with the dementia diagnosis. Just over 93% of respondents confirmed that insurance did cover the diagnostic tests, with none of the sample’s respondents stating that they did not have insurance for the diagnostic tests, and only 5% were unsure of whether or not the patient’s insurance covered the cost of dementia diagnostic testing.

Also in the survey, caregivers were asked to respond to questions related to the diagnostic process, their caregiving role, and community resources. Caregivers were asked about their level of understanding about the disease and their ability to provide care following diagnosis (See Table 4). Just over 84% responded they did not feel they had enough information about the disease at diagnosis. Caregivers were asked to reflect one year following diagnosis and determine if they then felt they had enough information about the disease. Nearly 49% of caregivers still did not feel they had been provided an adequate understanding of dementia and the person’s needs.

Several items were used to examine the caregivers’ knowledge of community resources. For instance, caregivers were asked how and when they came to know about the Alzheimer’s Association (See Table 5). When caregivers were asked if they felt they had enough information about available community resources at diagnosis, an overwhelming 93% indicated they did not understand what resources were available. When asked to reflect on how informed they were about available community resources following one year following diagnosis, 62% still felt they did not have enough information on care assistance. Additionally nearly 20% of caregivers did not learn about
the Alzheimer’s Association until 1 year or longer after the care recipient was diagnosed with AD or a related type of dementia.

Lastly, caregivers were also asked about what services they were currently utilizing (See Table 6). Caregivers were also asked about their rationale for contacting or failing to contact community resources. Although over 35% of caregivers reported calling the Alzheimer’s Association immediately after learning of its existence, many caregivers did not contact the association because they did not understand how the association would be beneficial to them (24%), they did not want or need assistance at the time (15%), family was hesitant (9%), caregiver was too busy to call (5%) or the individual was diagnosed with Alzheimer’s disease and the family did not realize they were still eligible for assistance with current diagnosis (5%). The majority of caregivers which participated in formal services were utilizing a long term care facility (26%), a county support program such as Senior Options (19%), adult day care (18%), or a home care agency (14%). Therefore, it could be assumed there was a good mix of individuals attending Alzheimer’s Association programs that are caring for an individual at home and others that have patient with dementia placed in a long-term care setting.
### Table 3
#### Experience with Diagnostic Process (N = 106)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type of doctor who gave current diagnosis</strong></td>
<td></td>
</tr>
<tr>
<td>Primary Care Physician</td>
<td>21.7</td>
</tr>
<tr>
<td>Neurologist</td>
<td>69.8</td>
</tr>
<tr>
<td>Psychologist</td>
<td>0.9</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>0.9</td>
</tr>
<tr>
<td>Other</td>
<td>5.7</td>
</tr>
<tr>
<td><strong>Types of diagnostic tests used for diagnosis</strong></td>
<td></td>
</tr>
<tr>
<td>Neuropsychological test</td>
<td>95.3</td>
</tr>
<tr>
<td>Brain imaging test</td>
<td>77.4</td>
</tr>
<tr>
<td>Laboratory test</td>
<td>67.0</td>
</tr>
<tr>
<td>Combination of neuropsychological, brain imaging, and laboratory testing</td>
<td>57.0</td>
</tr>
<tr>
<td>Testing Unknown</td>
<td>3.8</td>
</tr>
<tr>
<td><strong>Length of time it took to receive diagnosis</strong></td>
<td></td>
</tr>
<tr>
<td>First doctor’s visit</td>
<td>14.2</td>
</tr>
<tr>
<td>1-3 months of testing</td>
<td>27.4</td>
</tr>
<tr>
<td>4-6 months of testing</td>
<td>23.6</td>
</tr>
<tr>
<td>7-12 months of testing</td>
<td>17.9</td>
</tr>
<tr>
<td>1-2 years of testing</td>
<td>9.4</td>
</tr>
<tr>
<td>More than 2 years of testing</td>
<td>2.8</td>
</tr>
<tr>
<td><strong>Caregiver suspected dementia prior to physician confirming the diagnosis</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>77.4</td>
</tr>
<tr>
<td>No</td>
<td>19.8</td>
</tr>
<tr>
<td><strong>Family given a different diagnosis during diagnostic testing</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>30.2</td>
</tr>
<tr>
<td>No</td>
<td>68.9</td>
</tr>
<tr>
<td><strong>Insurance covered the diagnostic testing</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>93.4</td>
</tr>
<tr>
<td>No</td>
<td>0.0</td>
</tr>
<tr>
<td>Unknown</td>
<td>4.7</td>
</tr>
</tbody>
</table>

### Table 4
#### Caregiving Role (N = 106)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>At diagnosis, caregiver had information about disease and caregiving role</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>84.0</td>
</tr>
<tr>
<td>Yes</td>
<td>14.2</td>
</tr>
<tr>
<td>A year following diagnosis, caregiver had information about disease and caregiving role</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>49.1</td>
</tr>
<tr>
<td>Yes</td>
<td>44.3</td>
</tr>
<tr>
<td>Not applicable, hasn’t been one year from diagnosis</td>
<td>4.7</td>
</tr>
</tbody>
</table>
### Table 5
Knowledge of Support Services ($N = 106$)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>At diagnosis, caregiver had information about available community resources</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>93.4</td>
</tr>
<tr>
<td>Yes</td>
<td>6.6</td>
</tr>
<tr>
<td>A year following diagnosis, caregiver had information about available community resources</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>62.3</td>
</tr>
<tr>
<td>Yes</td>
<td>28.3</td>
</tr>
<tr>
<td>Not applicable, hasn’t been one year from diagnosis</td>
<td>4.7</td>
</tr>
<tr>
<td>Doctor referred caregiver to support program at diagnosis</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>63.2</td>
</tr>
<tr>
<td>Yes</td>
<td>35.8</td>
</tr>
<tr>
<td>Length of time after diagnosis it took caregivers to learn about Alzheimer’s Association</td>
<td></td>
</tr>
<tr>
<td>At visit when care recipient was diagnosed</td>
<td>21.7</td>
</tr>
<tr>
<td>1-3 months</td>
<td>17.0</td>
</tr>
<tr>
<td>4-6 months</td>
<td>14.2</td>
</tr>
<tr>
<td>7-12 months</td>
<td>10.4</td>
</tr>
<tr>
<td>1-2 years</td>
<td>3.8</td>
</tr>
<tr>
<td>More than 2 year following diagnosis</td>
<td>15.1</td>
</tr>
<tr>
<td>Already knew about association prior to diagnosis</td>
<td>17.0</td>
</tr>
<tr>
<td>How caregivers learned about the Alzheimer’s Association</td>
<td></td>
</tr>
<tr>
<td>Doctor</td>
<td>21.7</td>
</tr>
<tr>
<td>Area Agency on Aging</td>
<td>4.7</td>
</tr>
<tr>
<td>Community Center</td>
<td>0.9</td>
</tr>
<tr>
<td>Church or Temple</td>
<td>2.8</td>
</tr>
<tr>
<td>Support Group</td>
<td>5.7</td>
</tr>
<tr>
<td>Printed Media</td>
<td>13.2</td>
</tr>
<tr>
<td>Internet</td>
<td>17.0</td>
</tr>
<tr>
<td>Friends or Other Family</td>
<td>2.8</td>
</tr>
<tr>
<td>Healthcare Agency</td>
<td>17.9</td>
</tr>
<tr>
<td>Adult Day Care</td>
<td>0.9</td>
</tr>
<tr>
<td>Veteran Affairs (VA)</td>
<td>1.9</td>
</tr>
<tr>
<td>Other</td>
<td>6.6</td>
</tr>
</tbody>
</table>
Table 6
Use of Support Services (N = 106)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reasons caregivers did not contact Alzheimer’s Association</td>
<td></td>
</tr>
<tr>
<td>Didn’t need/want assistance</td>
<td>15.1</td>
</tr>
<tr>
<td>Were too busy to call</td>
<td>4.7</td>
</tr>
<tr>
<td>Didn’t understand how services would be helpful</td>
<td>23.6</td>
</tr>
<tr>
<td>Family was hesitant</td>
<td>9.4</td>
</tr>
<tr>
<td>Individual didn’t have Alzheimer’s disease</td>
<td>4.7</td>
</tr>
<tr>
<td>Not applicable, contacted right away</td>
<td>35.8</td>
</tr>
<tr>
<td>Types of services currently being used</td>
<td></td>
</tr>
<tr>
<td>Senior Options and other county aging program</td>
<td>18.9</td>
</tr>
<tr>
<td>PASSPORT</td>
<td>1.9</td>
</tr>
<tr>
<td>Adult Day Care</td>
<td>17.9</td>
</tr>
<tr>
<td>Home Care</td>
<td>14.2</td>
</tr>
<tr>
<td>Long Term Care Facility</td>
<td>25.5</td>
</tr>
<tr>
<td>Hospice</td>
<td>6.6</td>
</tr>
<tr>
<td>Veteran Affairs (VA)</td>
<td>10.4</td>
</tr>
</tbody>
</table>
CHAPTER 5  
DISCUSSION

The process of getting a diagnosis of dementia can be a challenging process for families. Dementia has been described as the modern epidemic of later life and is the most feared diagnosis of older adults (Bond & Corner, 2001). Additionally, diagnosis disclosure has been cited as one of the five most difficult aspects in dementia care by physicians and nurses (Bamford et al., 2004). On top of dealing with a devastating and fatal diagnosis, information and support that individuals and families receive during and following such diagnoses are often incomplete and inadequate. Family members, the patient with suspected memory loss, and the doctor that is assessing for dementia can contribute to delays in the diagnosis process (Boise et al., 1999; Bradford et al., 2009).

Once diagnosed, individuals with AD and related dementias often need assistance with many components of their daily living activities (Alzheimer’s Association, 2009). Family caregivers are vital in providing informal care, or coordinating providers to assist with care, to these individuals that are diagnosed. However, if caregivers are not properly supported through respite programs, the stress of caregiving can be detrimental to their physical, social, and emotional well-being (Pinquart & Sorensen, 2003; Son et al, 2007; Vitaliano, Zhang & Scanlon, 2003). Families who utilize support services in dementia care have found the care to be beneficial for the person with dementia as well as
the family, and can delay institutionalization of the individual (Gaugler, Kane, Kane & Newcomer, 2005), which is also cost-savings to the U.S. healthcare system (Alzheimer’s Association, 2010). Despite wanting and needing support services, caregivers are often unsure of the availability of such services and the way to connect with providers such as the Alzheimer’s Association (Adams, 2006). Many caregivers never end up accessing available services, mainly because of a perceived lack of need or awareness (Broadaty, Thomson, Thompson & Fine, 2005).

Currently, the majority of research on the subject of dementia diagnosis focuses on physician’s professional attitudes and practices (Bamford et al., 2004). It is still unclear what caregivers needs are during and after diagnosis, and how these caregivers come to connect to available support services within their communities. While many caregivers are interested in connecting to assistance and information about providing care and available resources, they often do not receive it (Laakkonen et al., 2008).

The purpose of this study was to further understand the experiences of caregivers during the diagnostic process, specifically looking to see whether or not families were experiencing challenges to diagnosis, and to identify what caregivers’ needs were throughout the diagnostic process. Additionally, the researchers questioned how caregivers learned about available support services, and how long and why caregivers waited to contact the Alzheimer’s Association following being informed of the offerings of their support programs.
According to national averages, African-Americans are about two times more likely and Hispanics are about one and one-half times more likely than their white counterparts to have AD and other dementias (Alzheimer’s Association, 2009). Results were not representative for minorities with AD, but this was due to the lack of minorities that responded. However, these results are representative of the population that the Alzheimer’s Association Central Ohio Chapter serves. Minorities are much more likely to be underrepresented within the association, as well as with support services in general (Prescop et al., 1999; Tuokko et al., 1999; Webber et al., 1994). This may be due to cultural implications associated with minority family members taking on more responsibilities as the primary caregiver without utilizing support services, limited access to medical care or it could be due to a lack of education for these caregivers about what services are available (Li, Edwards, & Morrow-Howell, 2004; Bazargan, Bazargan, & Baker, 1998).

**Diagnostic Testing**

One of the major findings from this study suggests that families are receiving diagnoses at a much quicker rate than past literature has suggested (Boise et al., 1999). Over 65% of Central Ohio caregivers indicated the memory loss diagnosis was made within six months. Previous studies found the mean time for the survey sample between symptom recognition and diagnosis was 29.7 months, with 19.1 months being the time it took for families to pursue physician consultation (Boise et al., 1996). In the last ten years awareness of dementia symptoms, physician training on diagnosis, and diagnostic testing technology has improved drastically (Alzheimer’s Association, 2009) which could
explain why individuals are receiving a much earlier diagnosis. There has been a huge push by the national chapter of the Alzheimer’s Association for individuals to be diagnosed earlier in order to have more opportunities to slow the progression of the disease through treatment (Johnson et al., 2000).

When examining how families received diagnosis, caregivers reported individuals diagnosed with a form of dementia received their diagnosis from a neurologist (69%), primary care physician (22%), or another health professionals. Additionally with findings related to diagnosis, most individuals diagnosed with Alzheimer’s disease or another related dementia received all three types of diagnostic tests (57%), however of all the diagnoses, 95% received a neuropsychological test, 77% received a type of brain imaging test, and 67% of persons diagnosed with dementia received a laboratory tests in the determination of the cognitive impairment.

Typically, one would expect all respondents to have received a laboratory test to rule out other possible explanations for the memory impairment, while neuropsychological tests and brain imaging are usually either the second or third step to diagnosis. The physical exam consists of the doctor collecting information about diet, nutrition, and alcohol consumption; reviews all medications; checks blood pressure, temperature, and pulse; and collects samples of the patient’s blood and urine. This test is the first step to dementia diagnosis as to rule out other disorders that display similar characteristics to dementia (Alzheimer’s Association, 2009). Possible explanations for this could be related to a surveying error with the word usage of laboratory tests with only the examples of “blood tests, etc.” which caregivers did not recognize. It is also
possible that they were not present during the doctor’s appointment where these tests would have been done and did not realize these steps had been taken as part of diagnosis. Additionally, it could be that more education is needed for caregivers to understand the entirety of the diagnostic testing process.

**Barriers to Dementia Diagnosis**

In the open-ended responses, when asked what would have been helpful during diagnosis many caregivers reported the diagnostic process going smoothly: “In my case the diagnosis process went fast and was fine”, “it went well”, “no problems with diagnosis”. However, some caregivers reported experiencing challenges during the diagnostic process including trouble getting the care recipient to see a doctor, hesitation from the doctor to connect the symptoms to dementia, difficulty getting the primary care physician to refer to a specialist, difficulty getting in to be seen due to offices not having available appointments, and caregivers not understanding the testing process. Caregivers expressed needs that ranged from “more information about what dementia was”, “I needed more time to talk with the doctor”, “better doctor availability”, “couldn’t get dad to go to the doctor”, and “doctor seemed reluctant to give diagnosis”. These are the same barriers individuals and families experienced to dementia diagnosis when sampled just over 10 years ago (Boise et al., 1999). More education may be needed prior to diagnosis for all parties involved in the diagnostic process to overcome these challenges and receive a more timely diagnosis.
There were also new challenges and barriers that emerged as the result of newer policies. Problems with patient confidentiality utilizing the HIPPA laws were also evident in the open-responses of caregivers, “Dad didn't give me permission to talk to the doctors, and so I had to send letters in before his appointment to talk to the doctor. It was extremely difficult to find out what was going on”. Caregivers have been very prominent in assisting with a family member’s diagnostic process, because they are able to provide a timeline for frequency of problem occurrence and typically have more insight into the people’s cognitive delays. While HIPPA laws are meant to protect patient confidentiality, it could have the potential to hinder quality of care for persons with cognitive impairments and dementia patients.

**Caregiver Knowledge of Diagnostic Testing**

Another significant finding from the study was the number of caregivers that admitted to suspecting dementia prior to their family member’s diagnosis being confirmed. Previous literature implies that diagnosis is a shocking and overwhelming experience for family members who are involved (Bamford et al., 2004; Wald et al., 2003), but almost 80% of all caregivers that participated in the survey responded to having suspicions that it was a type of dementia prior to confirmation of diagnosis. Additionally, a large number of caregivers responded in the survey that the diagnostic process of confirming a dementia diagnosis was overall a smooth process for them and their family members. While the disease itself is still very overwhelming to address and take on in the caregiving role, as more of the general public become knowledgeable about
the symptoms of AD and related dementias there is hope that the diagnostic experience for individuals and their families will become easier to acknowledge. Future studies should examine levels of caregiving understanding regarding symptoms of the disease and the impact education of AD and related dementia has on enhancing the diagnostic experience for caregivers.

Another interesting finding related to 30% of caregivers reported that their diagnosis changed from when testing started to the current dementia diagnosis. Some individuals were originally given explanations for symptoms related to depression, diabetes, and stress. However, many diagnoses changed due to the individual getting a more differential diagnosis moving from dementia unspecified to a specific type of dementia. This further shows the process of obtaining a dementia diagnosis can be a lengthy and complex process.

In addition, just over 16% of caregivers reported their loved ones were diagnosed with dementia unspecified. In the open-ended responses, many caregivers could not justify why they should pursue a differential diagnosis. Many caregivers’ questioned the benefit of pursuing additional testing because it did not greatly impact the treatment options that would be available with a more specified type of dementia diagnosis: “Our family is still deciding whether or not to pursue a ‘differential’ diagnosis since we don't know the type of dementia. My brother thinks it’s a waste of time and my sister thinks it’s important. I’m still not sure what we will do”. More education is needed for families regarding the importance of differential diagnosis and how it can benefit their loved one. Additionally, it could be argued more specialized treatments should be developed to
better meet the needs for specific types of dementia and the characteristics of each particular disease. Implications from the finding suggest if more education was available for caregivers during the diagnostic process about the importance of differential diagnosis it could impact a family in receiving a more complete diagnosis which can lead to better quality of care (Alzheimer’s Association, 2009).

Support Needed During and After Diagnosis

Once given a diagnosis, the majority of caregivers felt they were inadequately supported at the time of diagnosis and many caregivers were still felt unsupported one year following diagnosis. Caregivers responded that they did not have enough information at diagnosis about the disease and how to provide care for an individual with dementia. A year following diagnosis, approximately 50% of caregivers still felt they did not understand the disease and how to provide care for an individual with dementia.

When looking at the data from the questionnaires, an overwhelming 93% did not feel at diagnosis they were given enough information about available community resources that would assist with the care of the individual with memory loss. One year following diagnosis, 62% of caregivers still felt they did not have that information about available community resources. In the open-ended responses, many caregivers stated they wanted more information and support following diagnosis, from not knowing what was available to help, being wary to accept help, and wishing they had been given a starting point: (what would have been help after diagnosis was) “information stating help is around the corner. I learned by way of school of the hard knocks”.

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Connecting to the Alzheimer’s Association

Eventually, all respondents that participated in the study did come into contact with the Alzheimer’s Association. This is evident in that they were using a support or educational program at the Alzheimer’s Association, as that was how they were recruited for the study. Only 22% reported being referred to the Alzheimer’s Association at diagnosis by their doctors. For 10% of caregivers, it took 7-12 months to learn about the association and for 19% they had not heard of the association until a year following diagnosis. Many individuals reported always knowing that the Alzheimer’s Association existed, but to what level their understanding of services existed is still unclear. Some individuals learned from friends who had previously used services from the association, and were given names of staff to contact that had been found to be very beneficial in assisting to answer questions about dementia and what support services were available.

However, once informed about the association—many caregivers still did not immediately connect to the association. Of all respondents, 36% reported contacting the association following an introduction to the association and its’ services. Reasons for not contacting immediately included 24% of caregivers not understanding what programs and services were offered or how they would be beneficial, 15% not wanting or needing assistance at the time, 9% reported a family member being hesitant to utilize services or programs, 5% of caregivers were too busy to call at the time, and 5% did not understand services were available for those with a related dementia and not specifically Alzheimer’s disease. It is unclear how much detail families were given with the referral to the
association. Were families told what programs they offered? Did they understand how the association could offer benefits to their family? If families did not understand how the association would serve as a benefit to their family, it may have greatly impacted the family’s decision to contact or utilize the Alzheimer’s Association to gain information about the disease or available support services. Previous literature has shown caregivers do not utilize support services if they cannot connect how it is beneficial to them (Fortinsky et al., 2009).

One particular concern for caregiver access to support services was the data collected regarding if insurance covered the diagnostic testing. All respondents reported that the diagnostic process was covered by the patient’s insurance, except for 5% which were unsure if insurance covered the testing. With such high numbers of uninsured Americans, there is a concern that this particular population and their caregivers are somehow not being connected to the Alzheimer’s Association for support. Future studies should investigate explanations to this particular finding, and determine how uninsured families are providing care for a person with dementia and how much usage of these families are receiving from community support services.

**Other Methods for Connecting Caregivers to Support**

Educating more doctors about the referral process, and what services are available to dementia caregivers through the organization is one option that could help directly connect caregivers to a program that focuses on educating and assisting them in finding the resources and support to safely care for someone with dementia. One caregiver
explains in an open-ended response, “If my doctor would have told me to call the Alzheimer’s Association because they could help me, I would have done it that day”.

Additionally, if programs like the Alzheimer’s Association utilized the Internet more, they may be able to provide a better understanding to families about support services and what kind of assistance is available for caregivers. In the study, 17% of caregivers learned about the Alzheimer’s Association through the Internet. Some studies reported caregivers not utilizing support services in dementia care due to a general lack of knowledge regarding what services are available or why they could be beneficial in caring for an individual (Fortinsky et al., 2009; Brodaty et al., 2005). If programs could utilize the Internet more to provide information about what the services are being offered and how they are beneficial, it could connect more caregivers to information and support following diagnosis.

Another possible intervention would be to implement a community-wide program that could assist in connecting caregivers to appropriate support services. If caregivers do not connect to support services during the diagnostic process with the diagnosing physician, there is no guarantee they will ever have the opportunity to connect to any type of support service. Virginia’s Department for the Aging has found a way to increase the information pathways for available support services. Information about services linked within the community can be accessed through a computer networking program which operates under a "no wrong door" philosophy. This philosophy formally recognizes that individuals with healthcare needs may enter a range of different community service sites and that they are a high priority for assistance through respite and informational
programs. Each individual needing treatment will be identified and assessed and will receive treatment, either directly or through appropriate referral, no matter where he or she enters the realm of services. (Virginia Department for the Aging, 2008). If Central Ohio was to develop a no wrong door concept referral system, it is less likely that caregivers of persons with dementia would be more aware of available support services (regardless of information obtained at diagnosis), because there would be more opportunities for the information to be available through a variety of channels within the healthcare system.

**Implications for Social Work**

Many caregivers expressed the want for more time with doctor, more time to ask questions, more time to ask questions where the individual who had been diagnosed would not be present, and they wished the diagnosing doctor had been upfront with about what dementia was and what the care needs would be for the individual that was diagnosed. Some caregivers felt the doctors did not feel comfortable talking about dementia with the individual present: “I wish the doctor would have told me what to expect during the progression of the disease so I would have known what to expect”, “I needed a better explanation to understand the disease”, “I don’t think the doctor wanted to talk about what is was really because my husband was still in the room.”

In settings where both physicians and social workers are present, such as in hospitals or outpatient clinics where diagnosis may occur, healthcare professionals could consider adding the final stage to the diagnostic process where individuals and families
will be scheduled to participate in a counseling stage and social workers could be utilized to meet one-on-one with families (Derksen et al., 2005). Social workers would be able to perform a care consultation for the individual and family regarding the potential needs of the person with dementia, what skills would be needed to provide care for the individual, and what resources are available to connect to within their community.

Caregivers need to be aware of the behaviors associated with the disease, psychoeducational interventions to address these behaviors, techniques to address challenging communication barriers associated with the disease, address potential safety concerns for the individual’s living environment, participate in discussion on how to address independence issues such as when to decide when the individual can no longer drive, and discuss the needs of the individual regarding daily care (including eating, bathing, and other appropriate activities). Additionally, social workers would be knowledgeable of available support services within the community, familiar with techniques that can be taught to caregivers to cope with stress associated with caring for an individual with dementia, and be able to instruct caregivers where and how to get financial and legal components for the individual in order (Alzheimer’s Association, 2009).

It is also important to recognize that not every single type of support program will work for each family that has a loved one diagnosed with dementia. In the study, nearly 36% of caregivers reported that the diagnosing doctor referred them to a “support program”. However, 93% of caregivers responded that they did not have enough information about available community resources at diagnosis. The question becomes,
was the one referral enough for families based on what their needs were? Additionally, was that referral appropriate for that specific family? One caregiver responded in the open-ended questions, “The doctor referred us to a program we weren't eligible to participate in. We then went a year without any assistance before coming across the Alzheimer's Association on accident. I cried when I talk to the social worker on the Helpline because I was so frustrated. I needed some help”. Social workers often take roles in organizations as the professional to be responsible to refer clients to programs, as well as case manage client’s interaction in programs. Doctors are not trained to specialize in referrals to community programs because they are meant to be able to determine diagnosis and provide appropriate medical care. While educating doctors about available support programs for families of an individual with dementia could help them connect caregivers to resources, social workers may be the ideal profession to work with families on connecting to community resources following diagnosis because of their ability to understand eligibility criteria, determining what the care need is for the person with dementia and caregiver, and assist in planning how care will need to adapt as the disease progresses.

There are so many tasks for caregivers that accumulate following diagnosis; multiple planning sessions may be needed. Studies have found trying to inform caregivers with all the information that is needed to provide care is overwhelming and more than caregivers want to deal with at once (Wald, Fahy, Walker & Livingston, 2003). However, one initial visit could be beneficial in addressing urgent, immediate questions the family has following diagnosis as well as to provide information on
available resources. Many studies have found caregivers have responded very negatively to dementia diagnosis, with extremely high levels of grief being experienced, even when physicians felt caregivers handled the diagnosis very well (Connell et al., 2004; Derksen, Vernooij-Dassen, Scheltens & Olde-Rikkert, 2005; Lakkonen et al., 2008, Meuser & Marwit, 2001); and many respondents from the survey report having many questions they did not have answered following initial diagnosis.

Another way to explain why there is limited support following diagnosis why is to compare AD and dementia diagnosis to the diagnosis of another terminal illness. Breast cancer patients, for example, following their diagnosis schedule follow-up appointments with their doctor to discuss what type of treatment the patient will be participating in to try to reverse the disease (American Cancer Society, 2010). Not only is AD a progressive and fatal disease which has no survivors and damage from the disease cannot be reversed, but there are very limited treatment options available from the doctor to address symptoms of the disease. Most often, the professional is able to write a prescription and schedule an appointment six months or a year later to check in on how the individual is coping with the disease. Future studies may want to consider this concept of individuals and families being under-supported following AD and dementia diagnosis, due to the limited treatment options which are available—particularly from doctors which could explain why primary support in managing AD and dementia does not come from the physician, but maybe should come from other community professionals such as social workers.
Limitations of Study

This study has several limitations that should be considered when interpreting the findings. First and foremost, the method for collecting data was cross-sectional which limits the study in that it is just surveying the family at a particular moment in their experience of caregiving. Their responses of their experience with the diagnostic process were based upon what they remembered of their experience when the person was diagnosed with dementia. Additionally, the study focuses solely on caregivers that are already utilizing some form of support service, as recruitment was initiated through Alzheimer’s Association programming. This limits the ability to explain why some caregivers used support services and others did not. Recruiting from the point of diagnosis through doctors’ offices and clinics may help to reach individuals who do not utilize support services but have been diagnosed with a form of dementia. It also is not representative of caregivers and families who experienced challenges to diagnosis that still have not been able to connect to any type of support service.

In addition, the sample lacks diversity among the participants. Future studies should consider different and more sophisticated sampling methods and over sampling methods of minority populations (e.g. Asian, Hispanic) to create a sample that is larger and more representative of the overall Central Ohio population. Minorities are more likely to experience Alzheimer’s disease and related dementias due to their higher exposure to risks associated with the disease including their environment, social economic statuses, and that they are more likely to health conditions such as Diabetes and
high blood pressure which have recently been shown to be highly correlated with Alzheimer’s disease and other memory loss disorders. Additionally, minorities tend to be under-represented in actual statistics of those diagnosed because they are more likely to go longer without a diagnosis. More outreach work and research is needed to better explain this phenomenon and to better grasp the needs and experiences of minority family members transitioning into the caregiving role.

The majority of caregivers learned about the Alzheimer’s Association within six months of diagnosis, but it is unclear what information they gathered right away, or what programs they began utilizing following the contact. It is also unclear how satisfied they were with information and services they receive from the association. Finding out how caregivers feel about the association’s resources may allow for the organization to structure its services to be more effective for caregivers following diagnosis and to better enhance its programs to meet caregivers’ needs.

The survey questionnaire was also exploratory in nature and did not probe the depths of the experiences of caregivers during the diagnostic process. Follow-up studies should consider more in-depth surveys and mixed method designs, or in the form of qualitative interviews, to really grasp the caregivers and care recipients’ needs following diagnosis in detail. To better understand caregivers’ needs during diagnosis, a study should recruit caregivers that are currently experiencing the diagnosis process. A more comprehensive study that followed caregivers throughout the steps of diagnosis may better explain the needs at the time of diagnosis without asking caregivers to give a
retrospective analysis of their needs, which for some caregivers is asking them to recall years previous when they received the dementia diagnosis. Additionally, more details regarding the timeline for when caregivers came into contact with information on dementia care, as well as intensity of utilization of services may allow for better understanding of caregivers’ needs following diagnosis.

Conclusion

In this study, the researchers examine caregivers’ experiences with the diagnostic process and their familiarity in how to access information and community resources. While some caregivers reported diagnosis going smoothly, other caregivers described challenges and barriers causing delays in the diagnostic process, and problems for the caregivers following diagnosis.

The majority of caregivers utilized neurologists to receive their dementia diagnosis, and the patient received three diagnostic tests (laboratory tests, neuropsychological tests, and brain imagining tests) to confirm a memory loss disorder. Many individuals and families were receiving a dementia diagnosis at a much quicker rate than previous literature has reported, with the majority being diagnosed in six months or less. This data is promising that individuals and families are getting explanations for health concerns through earlier diagnosis, which can lead to more treatment options and more opportunities for the individual with dementia to be involved in their own care planning and healthcare decision-making.
The majority of caregivers learned about the Alzheimer’s Association within six months of diagnosis, most commonly from the patient’s doctor, friends and family, and the Internet. However, it is unclear what information caregivers were given upon referral to determine whether they understood what services were available or how utilizing the services would be beneficial to their families.

Based on this need described by families, social workers should be considered in healthcare settings where they are already part of an interdisciplinary team to engage in follow up informational meetings with family members, as well as be available for consultation with families to determine what the family’s needs are in order to provide care for a person recently diagnosed with AD or dementia. Social workers would be able to assess the family for the individual and caregiver’s needs and make an appropriate referral to a community agency that could provide such care services. Additionally, the social worker would be able to answer questions regarding the progression of the disease, what safety considerations need to be adjusted in relation to the individual’s independence, and how to address challenges in behavior, communication, and daily living activities that impaired by the progression of the disease.

Caregivers reported wanting more information and support than what was provided to them at diagnosis, and while they expect this information to come from the diagnosing physician, it usually does not. Caregivers reported being lost, feeling hopeless, and being frustrated from a lack of understanding regarding what the person diagnosed with dementia needed, and what was available to help them. Lack of treatment
options for AD and dementia could be partly to blame for the limited services physicians are able to provide to families following diagnosis. As physicians are not commonly the ones providing many of the treatment options available to AD and dementia families, utilizing social workers to assist families following diagnosis may better meet the needs of caregivers during and after diagnosis.
Dear Caregivers and Families-

My name is Allison Gibson and I am a graduate student working under the direction of Dr. Keith Anderson in the College of Social Work at the Ohio State University. I am conducting a research study focusing on the experiences of family caregivers during the diagnosis process. Specifically, I am trying to find out how your loved one was diagnosed and how you came to learn about support programs in your community.

There is an online survey available at the Internet link below. The survey should take about 6-8 minutes to complete. Your participation in this study is voluntary and all responses will remain confidential. If you have any questions regarding the study, please contact gibson.422@buckeyemail.osu.edu.

We will be collecting responses from caregivers for this study through the end of February 2010. Thank you for your time and your information will help us to better assist families during memory loss diagnoses.

Sincerely,
Allison Gibson
APPENDIX B: ORAL SOLICITATION

My name is Allison Gibson and I am a graduate student working under the direction of Dr. Keith Anderson in the College of Social Work at the Ohio State University. I am conducting a research study focusing on the experiences of family caregivers during the diagnosis process. Specifically, I am trying to find out how your loved one was diagnosed and how you came to learn about support programs in your community.

I will be passing out a very short survey at the end of this program. The survey should take about 5 minutes to complete. Your participation in this study is voluntary. If you have any questions or are interested in completing the questionnaire, please see me following the program today. I really appreciate your help with this project.
APPENDIX C: QUESTIONNAIRE

Alzheimer’s Association/The Ohio State University
Study of the Diagnosis and Support for Memory Disorders

The purpose of this study is to examine the experiences of family caregivers during and following the diagnosis of a memory disorder. This information will help to improve the way in which medical professionals communicate with families and help us to better serve you.

Please fill in or check the answers to the following questions.

Section I – Background & the Diagnosis Process

1. What is your zip code? __________
2. What is the gender of the care recipient? □ M  □ F
3. What is the race of the care recipient?
   □ White
   □ African American
   □ Hispanic
   □ Asian
   □ Other
4. What was the age of the care recipient at diagnosis? __________
5. What is the age of the care recipient now? __________
6. What is your relationship to the care recipient?
   □ Spouse/Partner
   □ Adult Child
   □ Brother/Sister
   □ Friend
   □ Other: __________
7. What is the current diagnosis for the care recipient regarding their memory loss?
   □ Alzheimer’s Disease
   □ Lewy Body Dementia
   □ Vascular Dementia
   □ Multi-Infarct Dementia
- Dementia Unspecified
- Frontotemporal Dementia
- No Diagnosis
- Other: ____________________

8. Who made this current diagnosis?
- Family Doctor
- Neurologist
- Psychologist
- Psychiatrist
- Other: ____________________

9. Where is this doctor’s office located?
- Urban (city)
- Suburban
- Rural (country)

10. What kind of diagnostic test(s) was used? (Please check all that apply)
- Neuropsychological Tests (memory tests, Mini Mental State Exam - MMSE)
- Brain Scans (MRI, CT, PET)
- Lab Tests (blood tests, etc.)
- Not Sure

11. Did insurance cover the diagnostic test(s)?
- Yes
- No
- Uninsured
- Not Sure

12. How long did it take to get this diagnosis?
- First Doctor Visit
- 1-3 Months
- 4-6 Months
- 7-12 months
- 1-2 Years
- Over 2 years
- We’ve yet to be given a diagnosis.

13. Did you suspect the diagnosis for the care recipient before the diagnosis was confirmed?
- Yes
14. Were you ever given a different diagnosis for the care recipient regarding memory loss?
   □ No
   □ Yes
   If No, please skip to question #15.
   If yes, what was this other diagnosis?

Section II – Support & Information following Diagnosis

15. At the time of diagnosis, do you feel you were given enough information about the disease and how to care for your loved one?
   □ Yes
   □ No

16. One year following the time of diagnosis, do you feel you were given enough information about the disease and how to care for your loved one?
   □ Yes
   □ No
   □ It has not been one year since the diagnosis.

17. At the time of diagnosis, do you feel you were given enough information about community resources to help care for your loved one?
   □ Yes
   □ No

18. One year following the time of diagnosis, did you feel you were given enough information about community resources to help care for your loved one?
   □ Yes
   □ No
   □ It has not been one year since the diagnosis.

19. Were you referred to any support programs by the doctor who diagnosed the care recipient?
   □ Yes
   □ No

20. How long after diagnosis did you first learn about the Alzheimer’s Association?
   □ Upon Diagnosis
   □ 1-3 Months
☐ 4-6 Months
☐ 7-12 months
☐ 1-2 Years
☐ Over 2 years
☐ I knew about the Alzheimer’s Association before the diagnosis.

21. How did you first learn about the Alzheimer’s Association?
☐ Doctor/Physician
☐ Area Agency on Aging
☐ Community Center
☐ Church/Temple/Mosque
☐ Support Group
☐ Printed Media (brochures, newspaper, magazines, books)
☐ Internet
☐ Television
☐ Friends/Family
☐ Healthcare Agency
☐ Adult Day Health Care
☐ Long-Term Care Facility, Home Health, Hospital
☐ Veterans Affairs (VA)
☐ Other:

22. If you didn’t contact the Alzheimer’s Association after learning about us, what was the reason(s)? (please check all that apply)
☐ Does not apply, we contacted you once we learned of the Alzheimer’s Association.
☐ We didn’t need assistance at the time.
☐ We were too busy to call at the time.
☐ We didn’t understand how the Alzheimer’s Association could be helpful to us.
☐ There was hesitation within family
☐ The care recipient does not have Alzheimer’s disease
☐ Other:

23. What programs do you or your care recipient currently use? (please check all that apply)
Alzheimer’s Association
Senior Options
Passport
Adult Day Health Care
Home Care Agency
Long Term Care Facility
Hospice
Veterans Affairs (VA)
Other: ______________________

24. What would have been helpful to you and your family during the diagnosis process?

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

25. What would have been helpful to you and your family following diagnosis?

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

Thank you for completing this survey. All of your answers will remain confidential and will be used for research purposes aimed at improving the services offered to caregivers and care recipients with Alzheimer’s disease and other memory disorders.
REFERENCES


Wolff, J. (2008). *Chronic Condition Data Warehouse, Data from OASIS Assessments*. Baltimore, MD: Johns Hopkins University, School of Public Health.