

**THE IMPACT OF SOCIAL POLICY ON ALZHEIMER'S DISEASE PATIENTS AND
THEIR FAMILY CAREGIVERS**

by

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OBJECTIVES: Alzheimer's disease (AD) is the most common form of dementia, the group of brain disorders that cause memory loss and decline in mental function over time. AD is the third most expensive disease in the nation, after heart disease and cancer. Average lifetime costs per patient are \$174,000 with annual estimates of \$80 to \$100 billion dollars in health care expenses and lost wages for the AD patient or their family caregivers. This study was designed to describe social policy and its affects on the eligibility and determination of benefits for two community-dwelling patients with AD and their caregivers in Southwestern Pennsylvania. The cases were purposefully selected to represent early age and late age of the onset disease and variability in service. **METHODS:** Secondary data analysis was conducted from data drawn from a previous study, "The Process of Medication Taking," (J. Erlen, PI). Data for the current analysis included participant observations, interactive unstructured informal interviews, open-ended formal interviews and case description. Constant comparative analysis was used to determine similarities and differences between cases. **RESULTS:** Family caregivers aim to achieve a stable community dwelling status for the AD patient. To achieve this objective, the family and patient's traverse a pathway of social care needs that include. Accessing social services, cultivating a social support network, maintaining continuity of care, and managing the

health care needs beyond the diagnosis of AD. Barriers to achieving the objective of a stable community dwelling status for the patient are social service eligibility, location to eligible services and inadequate support by family and friends. PUBLIC HEALTH SIGNIFICANCE: The number of AD patients has doubled since 1980 and is expected to continue to expand to 11.3 to 16 million people by the year 2050. Furthermore, much of the long-term care is being provided by the family caregivers. Programs such as Medicare, Medicaid and Social Security Disability Insurance do not cover all of the needs and financial obligations for patients and their families. Even after these public programs, families continue to remain financially responsible for the care of their family member. Therefore, policy focused on evaluating AD on the basis of diagnosis rather than social policy eligibility criteria, such as age, may be warranted to provide optimal benefits for patients and family caregivers.

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PREFACE

I would like to acknowledge those persons diagnosed with Alzheimer's disease and their caregivers who face the challenges of this disease, I am grateful for their stories. Without them, I would not have been able to complete this work.

I would like to thank Dr. Judith Erlen for providing me with the opportunity to analyze case studies from her project entitled "The Process of Medication Taking" funded by the Alzheimer's Association. Her generosity has been greatly appreciated.

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I would like to thank my friends, especially Gwende and Paul, who have supported me in numerous ways. I would also like to thank my co-workers, Judy, Lauren, Bridget, Peggy, Liza

and Margaret, who have been my cheerleaders and supporters as I have struggled to combine both work and study. I would also like to thank my family, my brothers and sisters, and nieces and nephews, especially little Sami and Alex, who were my stress relief when I needed some time away from my studies.

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1. INTRODUCTION

1.1. BACKGROUND & SIGNIFICANCE

Alzheimer's disease (AD) is a progressive brain disorder that gradually destroys a person's memory and ability to learn, reason, make judgments, communicate and carry out daily activities. As AD progresses, individuals may also experience changes in personality and behavior, such as anxiety, suspiciousness or agitation, as well as delusions or hallucinations. AD is the most common form of dementia, a group of conditions that all gradually destroy brain cells and lead to progressive decline in mental function. AD advances at widely different rates. The duration of the illness may vary from 3 to 20 years.¹ The areas of the brain that control memory and thinking skills are affected first, but as the disease progresses, cells die in other regions of the brain. Eventually, the person with AD will need complete care. If the individual has no other serious illness, the loss of brain function itself will eventually cause death.² An estimated 4.5 million Americans have AD. The number of Americans with AD has more than doubled since 1980.³ The number of Americans with AD will continue to grow – by 2050 the number of individuals with AD could range from 11.3 million to 16 million.³

Increasing age is the greatest risk factor for AD. One in 10 individuals over 65 and nearly half of those over 85 are affected.⁴ Rare, inherited forms of AD can strike individuals as early as their 30s and 40s.⁵ Symptoms of AD appear, in most cases, after the age of 65, also known as late-onset. However, approximately 5% of all Alzheimer's disease cases have an early-onset

(before the age of 65).^{6,7} Of the 5% of the population diagnosed with early onset AD, 61% had a positive family history for the disease and 13% had affected individuals in at least three generations.^{6,7} People with AD will live an average of eight years and as many as 20 years or more from the onset of symptoms as estimated by relatives. From the time of diagnosis, people with AD survive about half as long as those of similar age without dementia. Average survival time is affected by age at diagnosis and severity of other medical conditions.⁸

1.2. STATEMENT OF THE PROBLEM

AD is the 3rd most expensive disease in the nation, after heart disease and cancer, with an average lifetime cost per patient of \$174,000.⁹ Annually, an estimated \$80 to \$100 billion dollars are spent on health care expenses or lost in wages for the person with AD or their caregivers.¹⁰ Long-term care which includes family caregiving is part of the total health care expense for Alzheimer's patients and their families.¹¹ Of these, long-term care and family caregiving costs are considered the most important determinants of total cost. Increases in costs are due to disease severity and decline in activities of daily living (ADLs). Caring for patients at home with mild to moderate forms of AD increases indirect costs compared to those being cared for in nursing homes.¹² As in the past, the current trend is for patients to remain living in the community and typically with the caregiver.¹¹ Costs of service is important to AD economics because informal caregiving costs can shift to formal caregiving costs when the family caregiver is no longer able to provide care for the patient.^{13, 14}

1.3. PURPOSE OF THE STUDY

The purpose of the study is to examine social policy as it affects the eligibility and determination of benefits for community-dwelling (at home) patients with Alzheimer's disease and their caregivers in Southwestern Pennsylvania. An in-depth examination of social services and economic resources available to two patients with Alzheimer's disease and their caregivers will be analyzed. Specifically, the study will describe (1) social policy that affects patients with Alzheimer's disease and their family caregivers, (2) eligibility criteria for available services, and (3) the impact social policy has on the receipt of benefits for patients and family caregivers. No prior study has described the impact of social policy on the receipt of benefits to AD patients or their family caregivers in Southwestern Pennsylvania. I will describe these social policies and the affects they have on the eligibility and receipt of social services and benefits to AD patients and their caregivers.

2. METHODS

2.1. STUDY DESIGN

Case analysis using qualitative description¹⁵⁻¹⁷ of de-identified data from the original study funded by the Alzheimer's Association entitled "The Process of Medication Taking" (IRB #0309058, Judith Erlen, PI) will be performed by reanalyzing the original data set, in whole or part, using qualitative case comparison. Case analysis using qualitative description will be utilized to provide in-depth study and comparison of social policy surrounding AD benefits organized around the patient-caregiver experience.¹⁵⁻¹⁷ This study proposes to identify the social policy regarding AD benefits for patients and family caregivers. The analysis will focus on the social policy specifically eligibility, availability and equality of resources to AD patients and their family caregivers. Constant comparative analysis¹⁸ is used to identify similarities (or differences) in social services and economic resources available for Alzheimer's disease patients and their informal (family) caregivers. Analysis of social policy will evolve around the eligibility of the patients and family caregivers regarding access to social services and care. In addition, the level of benefits by policy will be compared to the actual benefits received by the patients and family caregivers.

Data for this study will be obtained from research study data files. These data were previously obtained from multiple sources including participant observations, interactive unstructured informal interviews, open-ended formal interviews, and case description.

2.1.1. SAMPLE AND SETTING

Comparative cases of two (2) community-dwelling patients and their family caregivers were purposively selected from the the original study funded by the Alzheimer’s Association entitled "The Process of Medication Taking" (IRB #0309058, Judith Erlen, PI). Table 1 provides the complete demographics of the patient sample. Purposive sampling was chosen to optimize the dichotomy and diversity between early-onset and late-onset Alzheimer’s disease.^{15, 16} Polar cases are used to illustrate how differing situations can produce common outcomes.¹⁶ In addition, the sample was selected for divergent representations of social services, caregiving and access to care. Furthermore, the “Mini-Mental State” examination, a cognitive mental status examination,¹⁹ for each of these patients represents additional similarities between cases. Although the MMSE is similar for these participants, their ability to perform Activities of Daily Living (ADLs) and Instrumental Activities of Daily (IADLs) living vary. Table 2 includes some of the participants’ ability to perform IADLs and Table 3 provides the ADLs. Table 4 provides complete demographics of the caregiver sample.

Table 1. Patient Demographics

	Early-onset Patient	Late-onset Patient
Age	51	76
MMSE ¹⁹	3	6
Gender	Female	Male
Race	Caucasian	Caucasian
Marital Status	Married	Widowed
Education	Masters’ degree	High school diploma
Primary Caregivers (s)	Spouse	Adult daughters (2)

Table 2. Instrumental Activities of Daily Living for AD Participants

Instrumental Activities of Daily Living (IADLs)	Early-onset Patient	Late-onset Patient
Do you use the telephone?	completely unable to use the telephone	without help including looking up numbers and dialing
Do you get to places out of walking distance?	with some help (need someone to help you or go with you when traveling)	with some help (need someone to help you or go with you when traveling)
Do you go shopping for groceries or clothes?	with some help (someone goes with you on all shopping trips)	completely unable to do any shopping
Do you prepare your own meals?	with some help (can prepare some things but unable to cook full meals yourself)	no opportunity to prepare meals and could not do so
Do you do your housework?	with some help (can do light housework but need help with heavy work)	no opportunity to do housework and could not do so
Do you take your own medication?	with some help (take medicine if someone prepares it for you and/or reminds you to take it)	with some help (take medicine if someone prepares it for you and/or reminds you to take it)
Do you handle your own money?	Complete unable to handle money	no opportunity to handle own money and could not do so

Table 3. Activities of Daily Living for AD Participants

Activities of Daily Living (ADLs)	Early-onset Patient	Late-onset Patient
Do you eat?	without help (able to feed yourself completely)	without help (able to feed yourself completely)
Do you dress yourself?	without help (able to pick out clothes, dress and undress yourself)	with some help
Do you take care of your own personal appearance, for example, combing your hair and (for men) shaving?	without help	with some help
Do you walk?	without any help or aids (except from a cane)	without any help or aids (except from a cane)
Do you get in and out of bed?	without any help or aids	without any help or aids
Do you take a bath or shower?	without help	with some help (need help getting in and out of the tub, or need special attachments on the tub)
Do you ever have trouble getting to the bathroom on time?	No	No
Is there someone who helps you with such things as shopping, housework, bathing, dressing and getting around?	Yes	Yes

Table 4. Caregiver Demographics

	Early-onset Caregiver (Husband)	Late-onset Caregiver (Daughter 1)	Late-onset Caregiver (Daughter 2)
Age	59	35	41
Gender	Male	Female	Female
Race	Caucasian	Caucasian	Caucasian
Education	Master's degree	Associate's degree	High school diploma
Employment Status	Full-time	Full-time	Full-time

2.2. DATA DRAWN FROM PREVIOUS STUDY

The data for this study are drawn from a previous project, “The Process of Medication Taking” (IRB #0309058 Judith Erlen, P.I.), a qualitative study funded by the Alzheimer’s Association, to examine the process of medication taking among persons with AD who live in the community. A purposive sample of 17 patients with AD and their family caregivers were recruited from the Alzheimer’s disease Research Center (ADRC) and community agencies serving the elderly. The researchers observed and audio-taped the preparation of daily medications and the taking of those medications on one to three occasions in each patient’s home. Brief interviews were conducted with the caregivers after each observation. An in-depth interview was conducted with the caregiver after the final observation. Brief interviews were also conducted with the patient, as appropriate, at the end of each observation. The field notes, observations, and the interviews were transcribed verbatim. Data for analysis consists of the transcriptions and descriptive data from the MMSE¹⁹ and Caregiver Vigilence²⁰ scale and participant profile.

2.3. DATA MANAGEMENT AND ANALYSIS

Textual files were entered into ATLAS.TI version 5.0 (Scientific Software Development, Berlin, Germany) for organization and data management. Each file was labeled with unique identifiers and data type (i.e. Interview data, observation, researcher debriefing notes).

The qualitative data analysis began with a thorough read of all textual documents to obtain a sense of the case story. After this initial read, guided by the research questions themes were identified and coded.²¹ Initially, types of caregivers and caregiving (family/outside the family) and financial assistance/support occurred repeatedly in the coding. A deeper review led to identifying different aspects of support, both financial and social services that contribute to access of care and services. Definitions were applied to each thematic code for consistent application to the remaining textual documents. The comparison of data within and between cases led to the sequencing of common and recurring information into themes, which were then mapped. Analytic memos were recorded to detail thoughts, incorporate social policy, and establish consistency.

Analysis meetings with a faculty mentor (MBH) expert in qualitative methods occurred monthly then weekly, at five time points during the analysis process to review themes, analysis, and the development of a model for rigor.^{22, 23} The mentor provided guidance in coding and oversight of the analytic process to provide auditability and fittingness as findings were validated and applicable.²²⁻²⁴ In addition, the examination of Death in Slow Motion²⁵, a personal account of the struggles of caring for an elderly parent with AD, provided confirmability and transferability of this data.²²⁻²⁴

2.4. LIMITATIONS

There are several limitations to this study. The results of the study are not transferable to all Alzheimer's disease patients and their family caregivers due to the fact that two case studies were examined, an late-onset case and an early-onset case. As such, this study serves as an illustrative exemplar of current policy and services for future examination of applicability to the larger population of community-dwelling AD patients. In addition, each case was located in differing settings, an urban county and a rural county, in Southwestern Pennsylvania. Examination of cases in a suburban setting and additional states is needed to further explore the impact of location. The fact that this is a secondary data analysis limits access to the participants, particularly for questions or additional data collection regarding the phenomena of interest.²⁶⁻²⁹ One of the biggest limitations is that social policy and service access were not the main focus of the original (parent) study.

2.5. HUMAN RIGHTS PROTECTION

A copy of the research protocol for "The Impact of Social Policy on Alzheimer's Disease Patients and their Family Caregivers" (IRB #0607055, D. DiVirgilio-Thomas, PI) was submitted to and approved by the University of Pittsburgh Institutional Review Board (IRB) for Human Subject Research. This IRB serves as the IRB for record for the University of Pittsburgh, Graduate School of Public Health. The principal investigator outlined the purpose of the study. There were no known risks to the study. (Appendix A.)

3. ALZHEIMER'S DISEASE OVERVIEW

Alzheimer's disease is the most common cause of dementia in older adults.³⁰ Dementia is a term used to describe the group of brain disorders that cause memory loss and the decline in mental function that occurs over time.¹ AD is the most common form of "primary dementia." Primary dementia is defined as dementia that is caused by changes in the brain that are not the result of another disorder such as cerebral thrombosis.¹ AD can often be confused with the normal aging process. In addition, there are two forms of AD, sporadic and familial. The familial type of AD is genetically predisposed resulting in family history of the disease. Whereas, the sporadic type of AD does not appear to have any genetic links for developing AD.¹

The most common early symptom of AD is short term memory loss.^{1, 31} As this disease progresses, symptoms tend to extend over the same general stages. Stages of the disease range from mild to severe. Figure 1^{1, 31, 32} represents the percentage of the United States population with AD by the severity of the disease. Symptoms span from simple and often fluctuating forgetfulness to deterioration of musculature and mobility in the later, more severe stages of disease.^{1, 31} Those persons in the mild stage of AD appear healthy but tend to become less energetic or spontaneous. In addition, it often takes time for them to make 'sense' of the world around them. There are changes in their behavior but these changes may go unnoticed by family members due to the subtleties of the changes.^{1, 32}

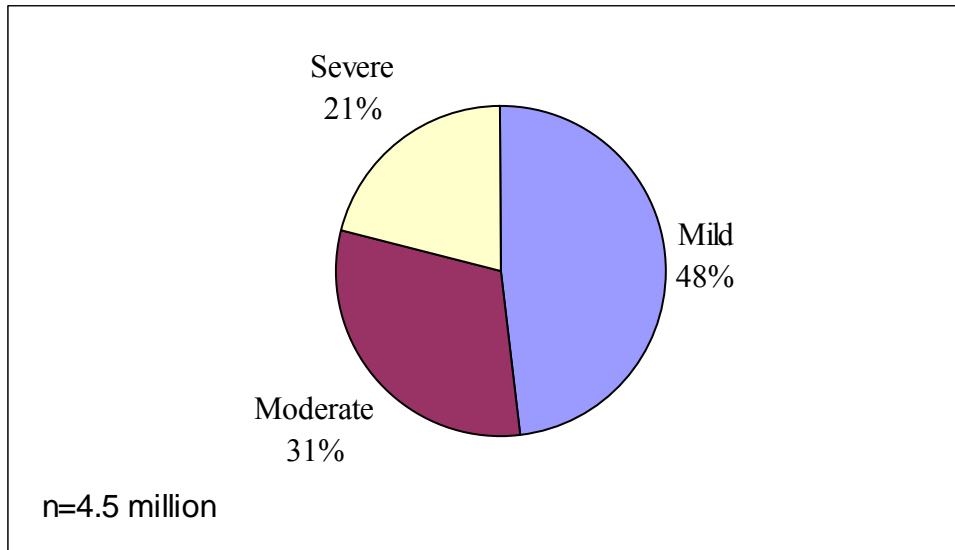


Figure 1. AD Population in the United States by Severity of Disease

In the moderate stage of the disease, these persons may continue to perform their daily activities independently but may begin to recognize changes in themselves or the severity of the symptoms. It is at this stage, they may also need assistance with more complex activities. Furthermore, the processes occurring in the brain begin to worsen causing greater damage in turn causing issues with language control, reasoning, sensory processing and thought.^{1,31}

In the final stage, the severe stage of the disease, the person will no longer be able to function without the assistance of others. The damage to the brains nerve cells will be widespread. It is at this stage when full time care is required. It is also at this stage when many individuals may become bedridden for long periods of time and often die from other acute illnesses.^{1,31}

Alzheimer's disease affects an estimated 4.5 million Americans.^{1, 3, 30, 33} Of those 4.5 million affected with AD, 0.3 million (7%) are between the ages of 65 to 74, 2.4 million (53%) between the ages of 75 to 84 and 1.8 million (40%) 85 years and older.^{1, 3} Figure 2^{1, 31, 32} represents the percentage of the United States population by percentage diagnosed with late-

onset Alzheimer's disease. By the year 2050, Alzheimer's disease could affect an estimated 11.3 million to 16 million individuals.^{1, 3, 34} Prevalence of AD in the United States are estimated to increase as the elderly population continues to grow. In addition, as the elderly population continues to grow, the distribution by age of the disease will also shift. This shift in age is the result of the aging of the "baby boomer" generation.^{3, 35}

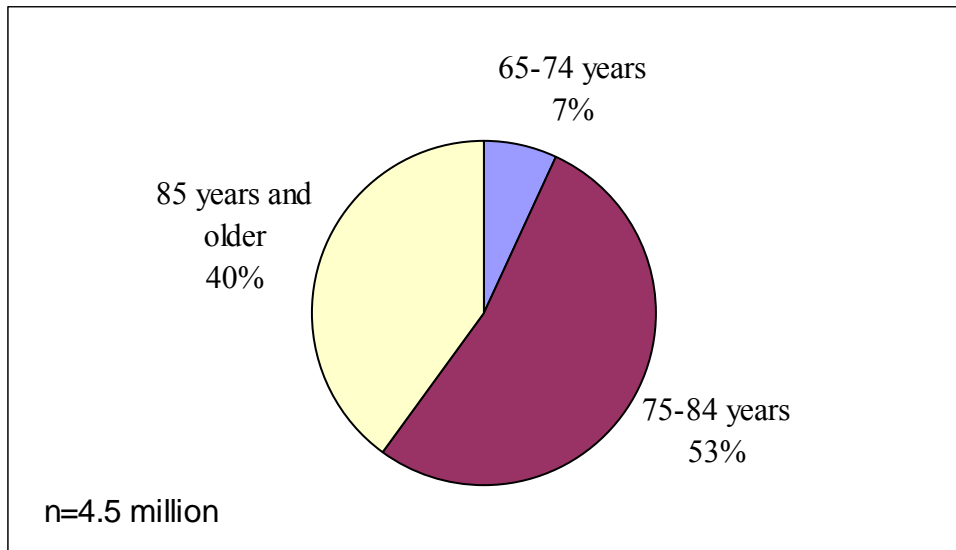


Figure 2. Age of US population diagnosed with AD

Common risk factors for AD are age, family history and the presence of the apolipoprotein E ϵ 4 allele.^{30, 31} AD is commonly associated with the elderly, 22% of people over age 65,^{4, 33, 34} 46% of people over age 75³⁴ and 31% of people over age 85^{4, 33, 34} are affected, however, individuals in their early 30's and 40's can be diagnosed with rare, inherited forms of the disease.^{5, 33} Women are at greater risk for the disease due to longer greater life expectancy.^{36, 37} In fact, two-thirds of the elderly population diagnosed with AD are women.^{34, 38}

3.1. EARLY-ONSET ALZHEIMER'S DISEASE

The most common cause of early-onset dementia is Alzheimer's disease.³⁴ Early onset Alzheimer's disease is defined or limited to onset prior to or younger than age 65 when the appearance of symptoms first begin.³⁵ It is difficult to diagnose early-onset AD in individuals.^{39,}
⁴⁰ Advanced brain imaging and improvements in neuropsychological testing have improved diagnosis of Alzheimer's disease to within 90% accuracy.³⁴ Younger age, healthy appearance and stress contribute to the inability to properly diagnose AD.^{39, 40} In addition, inaccurate diagnosis of depression or other psychiatric illness does not result in the diagnosis of AD.³⁹ Furthermore, when AD symptoms have been identified in an individual, different health care professionals may provide conflicting diagnoses.^{39, 41} Early onset AD patients are likely to be misdiagnosed more often than late-onset AD patients, have dementias other than AD, and/or have treatable or preventable etiologies.³⁶ Frustration levels increase for patients and family members as a result of their experience with and treatment by medical professionals, in addition to the extended delay in reaching a diagnosis. Further frustrations result from the prevalence of atypical dementias associated with this younger age group.³⁴

Young onset dementia is frequently familial. Prior to the age of 40, dementia is rare. Early onset AD may begin to manifest beginning in the fourth decade of life.³⁷ Early onset AD accounts for 5% of all Alzheimer's cases. Familial AD accounts for 61% of patients diagnosed with early onset AD. In addition, 13% of those affected with familial AD occurred in at least three generations. A prevalence rate of 35-41.2 per 100,000 persons at risk for early onset AD has been reported.^{38, 40}

The progression of early-onset dementia (EOD) is quicker than in late-onset dementia (LOD).^{42, 43} In addition, the severity of impairment of those diagnosed with EOD may be higher. Life expectancy of EOD patients compared to those with LOD is significantly reduced.^{42, 43} It is believed that diagnosis of early-onset dementia has three distinct elements: “(a) it may identify a treatable cause (more likely in younger people); (b) there may be time for appropriate management of legal and personal affairs; and (c) it may prepare carers and give access to early support.”^{39, p240}. Since the diagnosis of Alzheimer’s disease is rare and difficult, general practitioners are less likely to make a diagnosis of AD in those adults under the age of 65.³⁹

Patients diagnosed with early-onset dementia are in a dynamic and particularly challenging situation. It is believed all people diagnosed with Alzheimer’s disease maintain some insight about the progress of the disease, but may fluctuate at different times throughout the disease. It is also believed that younger people are more cognizant about the impact the disease has upon themselves, and their families.^{40, 43} It is difficult for people in their forties and fifties, at the height of their careers, saving for their retirements, to fathom being diagnosed with early-onset dementia, specifically Alzheimer’s disease. Many of those diagnosed with the disease are beginning to pay for or saving for their children’s college educations. While some are able to remain working, limiting their responsibilities, others must stop working completely causing financial hardship for their families. It is in the workplace where most symptoms are first recognized. Tasks become difficult to complete, directions are challenging to follow or angry outbursts occur at co-workers, which are atypical of the person.³⁴

They continue to maintain relationships with ageing parents, spouses and children. Many ageing parents of AD children find it difficult to see their child with Alzheimer’s disease.³⁹ The spouse experiences some level of personal upheaval, typically on an emotional level and on a

practical level. Spouses experience changes in role, responsibility and sexual relationships.³⁹ Comparisons have been made between children of EOD patients and those with mental health problems or degenerative disease. The difference, however, is that EOD presents several factors such as changes in personality traits, progressive deterioration, terminality of condition and a loss of role model. Early-onset dementia evokes powerful reactions in children of those affected by the disease. They may become frightened by the disease, by the unexplained behavior changes, leading to withdrawal emotionally, socially and often from the informal caretaking responsibilities of their parent.³⁹

We live in a society that highly values personal independence, which includes our ability to provide and care for ourselves and loved ones. Dependence is an attack on our identity, our personhood. There is some expectation of dependency as we age which is often considered normal or “on-time.” However, for those who are diagnosed with early-onset dementias such as Alzheimer’s disease, dependency is unexpected, difficult and adds additional stress for all of those people involved.³⁴

The diagnosis of Alzheimer’s disease is typically shocking or unbelievable to those who receive it, even though they may have had concerns that something was wrong. These feelings are intensified for younger people diagnosed with EOD because it is “unexpected and rare.”³⁹ p243. Many EOD patients experience feelings such as fear, grief, loss, frustration, loss of control, embarrassment, insecurity and isolation.³⁹ It has been reported many of these reactions are the same or similar to those people coping with chronic degenerative conditions and/or terminal illness, not exclusive of the elderly.³⁹

High levels of distress occur in early-onset dementia patients. This high level of distress is due to the rapid decline in their condition. The acknowledgment of coming to terms with EOD

can be traumatic and terrifying especially when dealing with the “erosion of the essence of self, a form of ‘decay from within.’”³⁹ p243. Memory loss in the elderly is a somewhat anticipated event. However, for EOD patients, the diagnosis comes unexpectedly. This diagnosis changes a young person’s life expectations greatly. Age appropriate activities such as employment, family caregiving, domestic activities and driving tend to cease. This illness essentially becomes terminal for a young person.³⁹

3.2. LATE-ONSET ALZHEIMER’S DISEASE

The progressive degenerative disease that affects cognition, behavior and the ability to perform activities of daily living, known as Alzheimer’s disease (AD), is a common disorder that affects a larger portion of the elderly population.^{35, 44} Estimates range from 5.7% to 10% of those aged 65 to 85 and 25% to 45% of those aged 85 years and older diagnosed with AD in the United States population.³² Alzheimer’s disease is the most common form of dementia accounting for 50% to 60% of all documented cases.^{32, 44} Associated with significant mortality, Alzheimer’s disease is the fourth leading cause of death for those persons aged 65 years and older.^{8, 32}

Difficulty in learning and retaining new information, increasing problems with affect calculation, visuospatial skills, performance of purposeful acts, and language characterize Alzheimer’s disease. Four hallmarks of Alzheimer’s disease are amnesia, apraxia, agnosia, and aphasia making AD one of the most feared diseases by the aging population.⁴⁵⁻⁴⁷ Risk factors for AD include aging; family history; presence of APOE4 allele (apolipoprotein ε genotype), lower education and gender.^{35, 46, 48} Estimates of the elderly population in the United States suggest the

incidence of AD doubles every 5 years of age from 1% to 2% at age 60 to more than 40% at age 85.^{36, 37}

There are indications that misdiagnosis and delayed detection of AD are common. This suggests that the actual incidence and prevalence rates of AD may in fact be much higher than reported.⁴¹ Reports of 30% or less of patients with symptoms consistent with AD have an initial diagnosis of Alzheimer's disease.³² Many of these symptoms, which are similar to non-AD types of dementia such as normal aging, depression, stroke and Parkinson disease, are often confused. Subtle early signs of Alzheimer's disease and gradual onset of symptoms cause a delay in diagnosis of AD until later in the course of the disease.^{32, 48}

Age-related memory decline occurs as the normal aging brain undergoes changes in structure and function. These changes are extreme in persons with Alzheimer's disease. Alzheimer's disease is predictable; however, the disease progression rate is not. This progressive decline, a predictable course, leads to declines in function and behavior that lead to loss of independence and eventual death. Loss of memory and other cognitive functions characterize the early stage of the disease.^{35, 44, 46-49} A progressive decline in the activities of daily living (ADLs) follows.^{48, 49} Behavioral changes or psychiatric symptoms appear. Utilization of resources of medical care increases which include nursing home placement.⁵⁰ There is often an eventual need for full-time assisted living or nursing home care before death.^{32, 44, 47} These changes affect not only the patient but also the caregiver, who is often burdened emotionally, physically, and financially.⁴¹ Consequently, the health care system is required to provide care for patients with AD as well as for caregivers.⁴¹

Rapid decline of cognitive function averages annually 9 to 11 point on the cognitive subscale of the Alzheimer's Disease Assessment Scale.³² The decline is reported at its slowest

during the mild to moderate stages of AD and most rapid during the moderate stage. Patients diagnosed with mild to moderate AD exhibit rapid decline within 2 years if left untreated.^{42, 51} Cognitive abilities are completely lost and are inaccessible in the severe stages of the disease.^{44,}
⁴⁶ The rate of cognitive, functional and behavioral decline is highly variable in Alzheimer's disease and is not a feature of normal aging.⁴¹

Alzheimer's disease patients experience a loss of interest in life. This comes with changes in personality, including distressing social withdrawal, uninhibited behavior and psychosis.^{47, 49} AD manifests behavioral and psychiatric disturbances. Increasing evidence suggest that these symptoms are associated with disease severity. Studies have shown that approximately 80% of patients exhibit behavioral and psychological symptoms at some time during their course trajectory.⁵² These symptoms manifest themselves as personality changes, irritability, anxiety and depression in the early stages. Increases in neuropsychiatric disturbances such as agitation, anxiety, restlessness, depression, day-night orientation, disinhibition, delusions and hallucinations occur in the moderate to severe stages of AD.^{44, 47, 49} Agitation manifests itself as yelling, screaming, physical abuse of carers, restlessness and swearing.⁴³ A major source of caregiver stress and a main contributor to the decision to institutionalize an AD patient are these behavioral and psychiatric symptoms.⁵²

The patient's loss of independent living is contributed by declining cognition and functional abilities. Early in the course of AD, many patients experience a unique feature of the disease, the loss of awareness of this deficit.^{44, 47} Emergence of feelings of denial, confusion, fear and guilt in the patient progress natural with the disease until cognitive loss is sufficient to leave the patients unaware of their condition.^{44, 47} The patient will lose most abilities to think, move, speak or perceive until ultimately death occurs.⁴¹

4. SOCIAL POLICY OVERVIEW

Dr. Alois Alzheimer diagnosed the first known case in a 51 year old patient by the name of Mrs. Auguste Deter in 1906. It is interesting therefore that Alzheimer's disease has become almost exclusively associated with aging. Because Alzheimer's disease is associated with aging, social policy focuses primarily on assisting those individuals aged 65 and older diagnosed with this disease. Unfortunately, for those individuals under the age of 65, this presents difficulties in accessing assistance both financially and psycho-socially. A range of public programs are available in the United States primarily geared toward the elderly. The major programs available to AD patients and their families include Medicare, Medicaid and Social Security Disability Insurance (SSDI). Estimated costs of formal and informal care annual in the United States for AD patient's care is \$100 billion with an average per person lifetime cost of \$174,000.^{1, 32, 47, 48, 52, 53} Medicare, Medicaid and Social Security Disability Insurance (SSDI) are not, however, deemed adequate to cover all of the financial obligations and needs of those with AD and their families.⁴⁴ Medicare, the United States health insurance program for seniors, spends on average 70% more for Alzheimer's disease patients than those with other chronic conditions such as heart disease, cancer or diabetes.⁴⁷ It does not however, cover long-term care, which is most needed. Many families and patients primary needs are for social services such caregiving services and respite ^{11, 33, 49}. Even after private insurance and public programs, families of AD patients

continue to remain financially responsible for care needs. The bulk of the cost of these home-dwelling patients falls upon these family caregivers.^{1, 11, 14, 44, 45, 48, 54}

The United States cost of Alzheimer's disease care is estimated to be at least \$100 billion in direct and indirect annual costs, ranking third after heart disease and cancer.^{1, 32, 52, 53} Direct medical costs, such as medications, physician visits, hospitalizations, and nursing home costs; direct nonmedical costs such as daycare and other social services; and indirect cost such as the time caregivers spend with patient and associated loss of productivity in the work place are all associated with the cost of Alzheimer's disease. Alzheimer's disease costs American business \$61 billion a year. Of that figure, \$24.6 billion covers Alzheimer health care and \$36.5 billion covers costs related to caregivers of individuals with Alzheimer's, including lost productivity, absenteeism and worker replacement.^{1, 11, 32} In addition, the progression of AD is associated with increasing costs, such that the cost of caring for patients with AD increases with increasing severity of the disease. Increasing disease severity also changes the cost determinants. Indirect cost often exceeds direct cost through out the early course of the disease because of home care. However, with progression of the disease to more severe stages, institutional care is required increasing the direct costs of care and shifting the cost burden to society from the caregivers. The health care systems incur considerable costs, which include residential care, day care, hospital services, diagnostic tests, monitoring or treating adverse events and outpatient visits.⁵²

Seven out of 10 Alzheimer's disease patients are living at home where family and friends provide almost 75 percent of their care.^{11, 14, 45, 48, 49, 54, 55} The remainder is "paid" care costing an average of \$19,000 per year.¹ This 'informal' caregiving contributes the services essential for the functionally disabled to sustain the long-term care they require. Statistically, one out of five functionally disabled elders end up in nursing homes to meet their long-term care

requirements.^{11, 14, 45} The remaining four out of five are able to meet their long-term care needs and continue living in their communities as a result of the care they receive from their family and friends.^{11, 14, 46, 54} The vast majority of this ‘informal’ caregiving is provided by the middle-aged adult daughter or the daughter-in-law. As a result of labor force trends, these typical ‘caregivers’ are being shifted into the workforce leaving a gap in the need for caregivers.^{11, 45, 46} These women are also often parents of minor children, thus earning them the ‘sandwich’ label.

The financial cost of care for AD patients begins at diagnosis with the annual costs increasing from diagnosis to death. Alzheimer’s disease patients who have their diagnosis recorded on medical claims records have approximately twice the annual expenditures of those with AD but without their diagnosis recorded on medical claims records.^{11, 14, 49, 55, 56} Families, the primary sources of care giving, are responsible for up to 50% of the costs for care of their loved ones with AD.^{11, 14, 47-49, 55} In addition, increasing levels of dependency by the affected AD patient increases the cost of care an additional 25%.^{11, 14, 44} Costs for a dementia patient are twice as much as that of a non-dementia patient.^{47, 49} Remaining at home is the desired goal of many patients and caregivers but can only be done so with support and assistance and at a cost.^{44, 45, 47, 55} As caregivers expend personal and economic resources, there is an increased likelihood that the patient will end up institutionalized. For many caregivers, this internal tension between caring for the AD patient and their own duty to keep the patient at home ultimately ends in asking for help in both caring for the patient but also managing the stress of caregiving.^{11, 46}

The federal and state programs that fund long-term care services all have eligibility criteria based on age and the presence of particular diseases and conditions. These eligibility criteria create major categories of people able to receive services: (a) elderly; (b) people with chronic physical diseases/conditions; (c) people with mental illness; (d) people with mental

retardation or other developmental disabilities; (e) people with human immunodeficiency syndrome; and finally (f) children with chronic illnesses and special health care needs.⁴⁸ Many of these programs that once used medical criteria as eligibility requirements are also using functional limitations instead or in addition to medical criteria.^{11, 48}

State governments play a key role in long-term care. State governments are responsible for not only matching federal funds for Medicaid long-term care programs, but also licensure and regulation of providers, establishment of benefit criteria and application processes, and an array of regulations and tax incentives affecting the many community services.^{49, 57-59} State governments adopt and actualize their policies in response to federal mandates or guidelines. However, states have flexibility and are permitted to exceed federal minimum requirements and to alter their programs as they deem necessary. There are many positive and negative effects of states' ability adopt policies. The wide range of benefits implies that federal requirements could be raised to reduce inequality.^{49, 57-59}

There is agreement among advocates, experts on Alzheimer's disease and policy makers that Alzheimer's disease patients should receive long-term care benefits.⁴⁹ The dilemma amongst these groups is in regards to what criteria should be used to identify their eligibility. Activities of daily living (ADLs) are the criteria most assume should be and will be used. The question remains as to how many of these ADLs are needed to meet the criteria, which ADLs should be included in this criteria and the threshold for decline in cognitive function and so on.^{49, 57-59} Criteria are the first step in this process. The next will be to determine the level of benefits, type, amount and duration based on the eligibility criteria. There is variance within and across states in the implementation process. States have scoring systems, which assign weights to risk factors

while others assign dollar allocations based on these scores. Some states processes are based solely on clinical assessment.⁴⁹

Medicaid expenditures are focused on nursing homes, accounting for the majority of its spending. Nevertheless, home health care services in states have increased in Medicaid spending from 10.8% in 1987 to 24% in 1997.^{12, 49, 55} Total expenditures for home health care in 2004 were \$71.1 billion for freestanding agencies.⁶⁰ Medicare paid 27%, Medicaid and other public funds paid 55%, private insurance and other private sources paid 11% and out-of-pocket costs were 7%.⁶⁰ (Figure 3)⁶⁰ It is estimated that Medicaid expenditures in 2001 will more than double by the year 2018 due to the aging population, rise in care costs, and general inflation.^{12, 49, 55} States provide home health services to individuals who are eligible for nursing facility services. These services include intermittent or part-time nursing services provided by home health agencies; registered nurses when there is no local home health agency; home health aides and medical supplies and appliances for home use.^{61]} In addition, personal care services are an option separate from home health care that can be offered under state Medicaid programs. Medical necessity or utilization control procedures are limits that can be placed on services under the Medicaid program. However, the Medicare statute and the regulations on Medicaid home health services enforce stringent requirements.^{12, 49, 55}

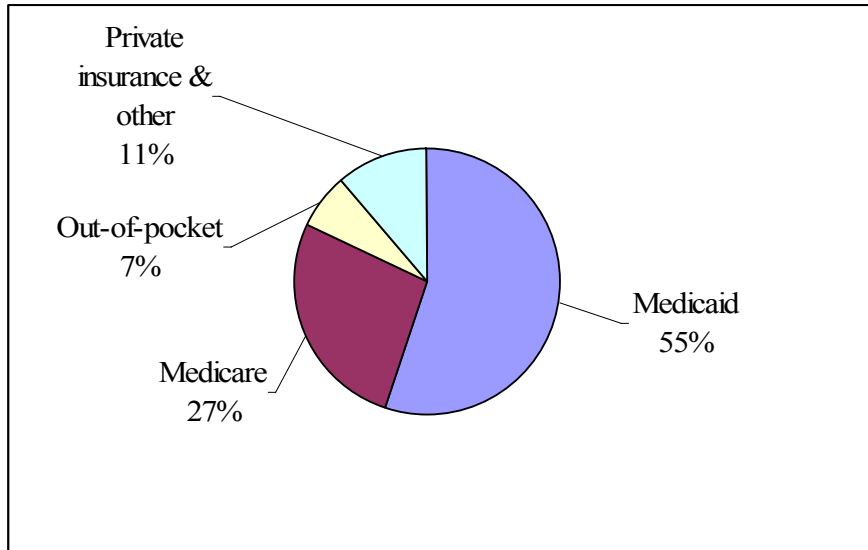


Figure 3. Funding of home health care

4.1. MEDICARE

Medicare is a federal health insurance program run by the Centers for Medicare and Medicaid, a federal agency part of the U.S. Department of Health and Human Services. This program is for people 65 years and older, some people with disabilities under the age of 65 and people with End-Stage Renal Disease.^{57, 62} Medicare is composed of four parts.⁵⁷ Part A covers hospital insurance, which most of those eligible for Medicare are not responsible for payment. Part B comprises medical insurance, for which those eligible are responsible for a monthly payment.^{57, 62} Part C provides for Medicare Advantage plans such as HMOs and PPOs. Finally, Part D encompasses the prescription drug coverage.⁵⁷ Additionally, those recipients determined disabled under Social Security Disability are automatically eligible for Medicare. Social Security will be discussed in the following sections.

Medicare Part A provides for inpatient care in hospitals, which includes critical access hospitals (small facilities that give limited outpatient and inpatient services to people in rural

areas), skilled nursing facilities (not custodial or long-term care), hospice care and home health care. Medicare Part A typically covers without having to pay a monthly payment, such as a premium. In addition, at the age of 65, most people receive Part A automatically. Receipt of Part A is without the responsibility for a premium and automatically at age 65 due in fact that the recipient or their spouse has paid Medicare taxes while they worked.^{57, 62} Furthermore, if you do not automatically receive this benefit premium free, there is the opportunity to be able to purchase it. Those who may qualify to purchase this benefit for a premium include the recipient and their spouse who are not entitled to Social Security because they did not work or pay appropriate Medicare taxes while they were employed and are age 65 and older. Additionally, a recipient who is disabled but no longer receives the premium-free Part A due to their return to work are may qualify to purchase this benefit.⁶²

Medicare Part B, which is optional, includes medical services such as doctors' services, outpatient care, and other medical services not covered by Part A. Part B provides assistance in the cost of medical services and items that are medically necessary. In addition, some preventative services are covered.^{57, 62} These preventive services include but are not limited to a one-time "welcome to Medicare" physical examination, bone mass measurement, flu and pneumococcal shots, cardiovascular screening, cancer screenings, diabetes screenings.⁵⁷ The premium for Part B in 2007 is \$93.50 per month. However, premiums are based upon income and may be higher for certain individuals. For those whose premium may be higher they include a recipient filing as single on an individual tax return with an annual income greater than \$80,000 or recipients filing as married on a joint tax return with an annual income greater than \$160,000. Furthermore, these amounts fluctuate each year.⁵⁷

Medicare Part A and B do not cover all medical needs. Cosmetic surgery, health care while traveling outside of the United States with limited exceptions, hearing aids, most hearing exams, long-term care such as nursing homes, most eyeglasses are just a few medical needs not covered under these sections.⁵⁷ However, they may be covered under Medicare Advantage Plans (Part C).

Part C or Medicare Advantage Plans are optional health plans offered by private insurance companies and approved by Medicare. These plans provide all of Part A and Part B coverage, and must cover medically necessary services. Part C encompasses extra benefits and may include Part D drug coverage. Plus, plan doctors must be seen and certain hospitals must provide the covered services. Typically, a monthly premium is paid in addition to the premium for Part B. The costs will vary by plan and services utilized.⁵⁷

Part D is the prescription drug coverage offered to all recipients with Medicare. Part D coverage provides protection for people who have very high drug costs or from unexpected prescription drug bills in the future. Additionally, it provides greater access to drugs that are used to prevent complications of diseases and maintaining a good health status. Part D is optional, run by insurance companies and other private companies and are approved by Medicare. Again, a monthly premium is paid. Decision not to enroll in this plan upon initial eligibility may result in a penalty if the decision is made to join later. Limited income and resources may qualify a recipient for assistance in paying Part D costs.⁵⁷

Part D covers both brand-name and generic prescription drugs. All Medicare recipients are eligible for this coverage regardless of income and status, health status, or current prescription expenses. There are two ways to get the Medicare Part D prescription drug plan. The recipient may join the Medicare prescription drug plan, a Medicare Advantage Plan, or other

Medicare Health Plan that offers drug coverage. In addition to the monthly premium and like other insurance plans, there is a yearly deductible, which varies by plan. Furthermore, the recipient will be responsible for costs of prescriptions including copayments and coinsurances. Moreover, recipients will be responsible for the first \$250 in drug expenses, and then will pay, on average, a 25 percent coinsurance until they reach the benefit limit (\$2,250 in 2006). Once they reach the benefit limit, they will face a gap in coverage in which they will pay 100 percent of their drug costs up to \$5,100 in total drug spending (equal to \$3,600 in out-of-pocket spending). Medicare will then pay 95 percent of drug costs above that amount.⁶³

4.2. MEDICAID

Medicaid is a federally established program administered through each state. This program provides benefits for medical to low-income people. Under the federal guidelines for this program, each state must include certain types of individuals and groups. There are three eligibility groups at the state level: categorically needed, medically needed, or special groups. For the purposes here, concentration is placed upon the medically needed.^{64, 65}

The medically needed are defined as people who have too much money, which includes resources such as savings. Not all states provide for the medically needed, but if they do they must include pregnant women through a 60-day postpartum period, children under age 18, certain newborns for one year, and certain protected blind persons. In addition, states may also opt to provide aged persons (age 65 years and older), disabled persons (disability has been determined using either the Social Security Insurance program standards or state standards), and

persons who would be eligible if not enrolled in a health maintenance organization. The state of Pennsylvania does provide for the medically needed.^{64, 65}

State programs are required at a minimum to provide the following services: inpatient and outpatient hospital services; physician, midwife and certified nurse practitioner services; laboratory and x-ray services; nursing home and home health care for individuals age 21 and older; early and periodic screening, diagnosis and treatment (EPSDT) for children under the age of 21; family planning services and supplies; and finally rural health clinic/federally qualified health center services. States are required at a minimum to provide home health services to recipients who are eligible to receive nursing facility services under the state's Medicaid plan. The elderly/disabled are automatically eligible for Medicaid based on eligibility for Social Security Insurance.⁶⁴ However, there are established resource limits. For one person the limit is \$2000; for two people it is \$3000.^{58, 64, 65} For those individuals aged 65 or older, disabled or blind and are not receiving Social Security Insurance, there are income limits. For one person the limit is \$250, for two people it is \$1000.⁵⁸ For the medically needy only limits the income limit is \$2400 for one person, \$3200 for two people and \$300 for each additional person.⁵⁸

An extension to Medicaid is waivers, provided through the Centers for Medicare and Medicaid Services, to allow states the opportunity to provide home and community services. Medicare waivers come in various forms and vary by state. Pennsylvania offers 11 waivers that provide benefits to many different populations including those aged three and under and the elderly. The Managed Care/Freedom of Choice Waivers [1915(b)] is requested to administer programs impacting the delivery system of some or all of the recipients eligible for Medicaid by state. These include mandatory enrollment of beneficiaries into managed care programs and developing a delivery system for specialty care. This waiver program is not required to be

implemented statewide. In addition, it may not be used to broaden eligibility requirements to include those ineligible applicants under the current, approved state plan. Furthermore, it is not permitted to impact beneficiary access, quality of care services and must be cost affective.⁶⁶ The HCBS waiver [1915(c)] permits states to offer an unlimited array of services to consumers. Traditional medical services, such as dental services, skilled nursing services, and non-medical services, such as respite, case management, environment modifications are supplied by this waiver. Furthermore, family and friends of the recipient are eligible to be providers of the waiver service once provider qualifications are met.⁶⁶ Finally, a state may choose to employ waivers, 1915(b) and 1915(c) to administer a continuum of services to the disabled and/or elderly populations. Subsequently, the 1915(b) authority to limit freedom of choice and 1915(c) authority to target eligibility and provides home and community-based services, states are not able to offer long-term care services in a managed care environment of use a limited pool of providers.⁶⁶

Two of the waivers the state of Pennsylvania offer are the ‘Pennsylvania Department of Aging (PDA) waiver’ and the ‘Long Term Care Capitated Assistance Program (LTCCAP)’. The PDA waiver provides home and community based services to eligible persons age 60 or older that are clinically eligible for nursing facility care. Eligibility criteria for the PDA waiver include individuals age 60 or older, income limit must be equal or less than 300% of the Federal Benefit Rate and resources are \$2000 or less. In addition, the individual must have a level of care for Skilled Nursing Facility. Some of the services available under this waiver include but are not limited to personal care services, home health aides, older adult daily living centers, specialized medical equipment and supplies and transportation services.⁶⁷ The LTCCAP waiver program is a health care and supportive services program designed as an alternative to nursing

facility care for qualified older Pennsylvanians. There are two sets of criteria for eligibility. The financial eligibility requires a \$2000 resource limit and an income limit 300% the Federal Benefit Rate. The functional eligibility requires individuals aged 60 years and older and be eligible for nursing facility services. Services for this waiver include but are not limited to in-home supportive care, personal care, pharmacy services and medications, adult day health services, and nursing facility services. The individual must be residing at home at the time of enrollment, in a domiciliary care home with prior approval or a long term nursing facility when needed to receive this benefit. Eligible programs are currently located in Allegheny County, Beaver County and certain areas of Philadelphia County.⁶⁷

4.3. SOCIAL SECURITY DISABILITY

Social Security Disability is administered through Social Security Administration with the intent to provide benefits to those people who are unable to work due to a medical illness which is expected to last a minimum of a year or result in death. Earning requirements have been set for those with a medical disability to receive this benefit. Benefit recipients must meet two separate earnings tests. The first earnings test is based on the recipient's age at the time they became disabled. The second earnings test is to show that the recipient has worked for a mandatory period to be eligible to receive Social Security.⁵⁹

Upon application for Social Security Disability, earnings test must first be met. If the applicant meets these requirements then their application is reviewed by the Disability Determination Office in their home state. It is the state office that then determines receipt of benefit. The process of decision includes disclosure of health status by one's own attending doctor. The state agency needs to know the following: a) What your medical condition is, b)

When your medical condition began, c) How your medical condition limits your activities, d) What the medical tests have shown, and d) What treatment you have received. Additional information may also be needed such as one's ability to perform work-related activities.⁵⁹

The Disability Determination Office in the applicant's home state proceeds through a five step process to make the final determination of disability status.⁵⁹ These steps include: a) Are you working, b) Is your medical condition 'severe', c) Is your medical condition on the list of impairments, d) Can you do the work you did before, and e) Can you do any other type of work.⁵⁹ The agency reviews the applicant's work status. By doing so, if the applicant is working, the agency will then assess the amount of money being earned a month. There is a limit as to the amount a disabled person is able to earn. If the applicant is earning more than the limit, the agency will determine the applicant is not disabled. However, if the applicant does not make more than this limit or is not working, then the agency moves to the next step and reviews the medical records. Upon reviewing medical records, the agency seeks to determine whether one's medical condition limits or impairs one's ability to perform basic work responsibilities. If the agency determines that the medical condition is severe, the agency will progress to the next step. The agency has a List of Impairments describing medical conditions defined as severe automatically labeling the applicant as disabled. If the applicant's medical condition is not provided on this list, then the agency will compare the applicant's medical condition to those on the list for its severity. Once it is determined that the medical condition meets the severity criteria, the agency will then consider whether the medical condition prohibits the applicant from performing those work responsibilities they performed previously. When the agency determines that the applicant is unable to perform these same responsibilities, it will then consider whether the applicant can perform other work responsibilities. If the applicant is unable to do so, the

agency finally decides that the applicant is disabled.⁵⁹ Once an individual has been determined disabled, they are automatically eligible for Medicare benefits.

4.4. PACE

The Program for All Inclusive Care for the Elderly (PACE) is a unique program available for both Medicare and Medicaid recipients. The program was designed to assist older people, who are frail and meet their State's standards for nursing home care. Benefits to the recipients include comprehensive medical and social services available through adult day health centers, home, and/or inpatient facilities. The comprehensive service package permits the elderly to continue living at home while receiving services, rather than be placed in a nursing care facility. Assessment is conducted by a team of doctors, nurses, and other health professionals who determine participant needs, develop care plans, and deliver all services, which are integrated into a complete health care plan. PACE is available only in States, which have chosen to offer PACE under Medicaid.⁶⁸⁻⁷⁰

Eligibility for PACE includes age criteria of 55 years of age and older and residence within the PACE service area. Additionally, the participant must be screened by a team of doctors, nurses, and other health professionals and determined to meet the state's nursing facility level of care. Finally, the participant, at the time of enrollment, must be able to safely live in the community setting.⁶⁸⁻⁷⁰

This program was modeled after the On Lok Senior Health Program in San Francisco, California. The program model was then tested through the Centers for Medicare and Medicaid Services demonstration projects beginning in the mid-1980s. This model addresses the needs of long-term care recipients, providers, and payers. Capitated financing permits the providers to

deliver participants all services needed rather than limiting them to the services reimbursable by Medicare and Medicaid fee-for service systems.⁶⁸⁻⁷⁰

There are nineteen states who participate in the PACE program. In the state of Pennsylvania, specifically, there are four providers. These providers are located in Philadelphia (2) and Pittsburgh (2). More specifically, Pittsburgh has two established programs, Community LIFE and LIFE-Pittsburgh Inc. The eligibility criteria for these facilities are as follows: at least 55 years of age and eligible for Medicaid or have the ability to private pay. In addition, they must have health related problems that make it difficult to manage their own needs independently at home, qualify for nursing home level of care, and be able to live safely in the community with the services provided. The recipient of this benefit must, however, reside in specific zip codes.⁶⁸⁻⁷⁰ These facilities provide a range of services that include but are not limited to day center services, adult day care, meals, and transportation. Additionally, a medical suite provides, but is not limited to, prescription services, primary medical care, nursing and laboratory tests and procedures. The in-home services include skilled nursing, personal care and chore services. Outpatient services provided through this program include specialist services, medical specialists, audiology/hearing, dentistry, optometry and podiatry. The inpatient services provide through this program include hospital, nursing home and inpatient services.⁶⁸⁻⁷⁰

5. STUDY RESULTS

The results and analysis from these two exemplar cases are presented as an integration of excerpt and social policy analysis. This integration of case data and commentary is a common approach in qualitative research.⁷¹ A comparative case study of two community-dwelling Alzheimer's disease patients and their family caregivers focusing on social policy specifically eligibility, availability and equality of resources are presented. Comparison and analysis of these two cases are used to illustrate and further examine details of social policy in the context of the lives of real families experiencing AD. The late-onset AD patient, referred to from here on as "Robert", is a 76 year old Caucasian man. Robert was married but has been widowed for nearly two years. He is currently retired. Robert is the father of four adult children; two sons and his two daughters who undertake primary caregiving responsibilities. He owns his own home which he visits daily with a male aide. He resides with his two daughters residing half of each week with each. Robert receives Medicare benefits, Social Security Insurance (SSI) and a pension. His insurance covers all costs of medication and health care.

The early-onset AD patient, referred to from here on as "Lucy", is a 51 year old Caucasian woman. She has been married for twenty-seven years and continues to live with her husband and daughter in their home. Lucy is the mother of two children, a son and daughter. Lucy receives Social Security Disability and Medicare benefits as a result of a psychiatric disability and private health insurance through her husband. Her insurance pays for the majority

of her medications for which there are copays. In addition, most of the costs for her health care is although there is a copay.

In-depth analysis and comparison of two case studies reveals a pathway of social care needs among community dwelling Alzheimer's disease patients and their family caregivers. The objective of the family caregiver is to maintain community dwelling status for the patient. The caregiver strives to achieve this through a process of accessing social services, cultivating social support networks, maintaining continuity of care and managing the health care needs beyond the patient's diagnosis of Alzheimer's disease. Achieving this objective begins at the diagnosis of Alzheimer's disease with alternation between these aims. (See Figure 4) However, maintaining community dwelling status of the patient can be a fluctuating process. There are barriers and setbacks to achieving a stable community dwelling status for the patient such as service eligibility criteria, proximity to services (location) and/or a lack of social supports such as family and friends resulting in the need to readdress other areas in the process.

The family caregiver's focus of attaining a stable community dwelling status for the patient is the patient and the patient's care. As one family caregiver stated, "I mean it, none of this is about me... Um, you know it's about them and it's about him and whatever it takes to make it easier for him is what I think we need to do, you know?" An aspect of preserving community dwelling status of the patient is facilitating the ability of the patient to remain living in the community setting. There is a high tolerance and patience on the part of these family caregivers in addition to a sense of filial duty and obligation.

[Daughter, LOD] *"Or if he would get to the point where he was smearing stuff all over the walls. Then, that might be something that I don't think is an option for my children to witness. If that's not it, there's no option, he stays... You know he*

just stays with us. You know? That's the way we all look at it anyway. None of us are faltering at all with him, 'cause he, you, you know. He worked two jobs almost all his life to make sure we ate. You know, the least we can do is take care of him. You know ... make sure he's safe."

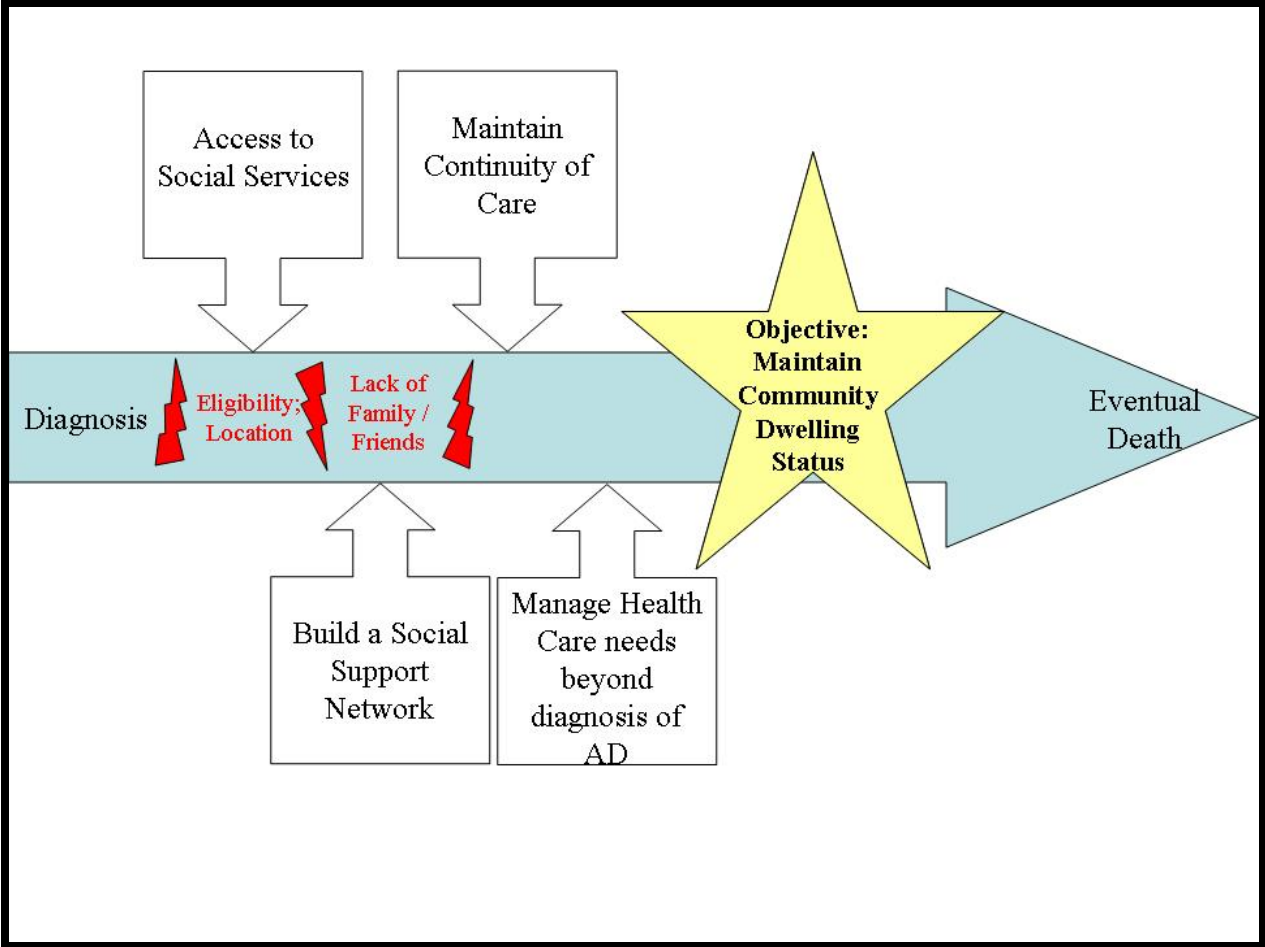


Figure 4. Pathway to Social Care Needs for Community Dwelling Alzheimer's disease Patients and their Family Caregivers

5.1. ACCESS TO SOCIAL SERVICES

On the route to maintaining community dwelling status of the patient, a primary step for the family members is to access social services for both financial and social support. The social support that a family caregiver and patient receive comes in the form of support groups, day care, respite care, and financial assistance. Accessing these services however is dependent upon eligibility criteria and location. Eligibility criteria for social services are dictated by the age of the recipient, most typically 65 years and older. This can create frustration for the families of patients diagnosed with early-onset Alzheimer's disease.

[Spouse, EOD] *“Nothing kicks until you’re in your 60’s. There’s nothing. So between that and the fact that she can’t qualify for the trials because she doesn’t do well enough on the tasks or she’s not old enough, again, got to be 56 for most of them, it’s frustrating. ...it’s so frustrating for me because number one (in a rural county in Southwestern Pennsylvania) there are no support services around because she’s 51.”*

[Spouse, EOD] *“There’s been no help here in town at all. I mean, you know, I went to aging services, we, they have a daycare center over there, we thought maybe she could go over there and just pretend she’s working. They didn’t want to hear it. Maybe it’s the liability issue, probably. You know, but there’s no adult daycare in town, there used to be a couple Alzheimer’s daycare units, they stopped it. There’s a big Presbyterian home here in town. She was so bad in*

December; her parents were insisting we were going to put her in the Presbyterian home. And we went out there and I went to the Alzheimer's unit, and I said I don't want to do this. I said, these people are all in their 70s..."

Access to services for those patients 65 years and older is much easier and more readily available. The late-onset patient in this study was able to receive several types of social services which included an adult day care, in-home caregiver (male aide), and help with medication prescription which enables the patient to remain living in the community setting. Robert, a late-onset AD patient, began using Adult Day Services since his wife was in such ill health, and has had experience with Adult Day Care for a while. This is not new to him. He lives 3 ½ days with (younger daughter) and 3 ½ days with (eldest daughter). Every other month the daughters "switch" and alternate weekends; otherwise one family never seems to get a weekend to go to movies or anything, which (eldest daughter) children had begun to complain about, never being able to go and do things on the weekends when "Pap Pap" was there. Each day upon leaving the Adult Day Care Center, Robert goes to his own residence in a Borough (in an urban county in Southwestern Pennsylvania) from about 1pm to approx 430pm when one of the daughters picks him up to go to their home. During this time period in his own residence, he is attended by a male aide from the Adult Day Care Center.

[Daughter, LOD] *"We share custody; we have 3 ½ days a week. He's here from Sunday at 10 in the morning till Thursday morning and I get him on the van, and she picks him up from his house with the caregiver on the van Thursday night and keeps him till Sunday morning. We do that, we rotate that every month. Every*

other month, one family member's got the weekends off and the other family doesn't. My husband's a city officer ... for two years we did all weekends and the kids were going bonkers. You know, cause they didn't have any weekend time, cause we had Pappy. You know Pappy had to be home for his nap and you know, this that and the other thing, so we couldn't do that. So anyway, it works out better that way. So, we share with her."

[Daughter, LOD] *"...The daycare because it's like the all inclusive medical clinic thing. And we just said "you know what, we're having some swallowing issues here. What do you have chewable, what do you have liquid?" And Anna Marie, his nurse, came back and said, "I can get the potassium in liquid," she said she could get the Celexa in liquid. Um, but right now, we're not havin' a problem with the morning pills."*

In contrast, the parents of the Lucy, the early-onset patient, pay out of pocket for an outside caregiver. Lucy's husband is unable to afford this service. Although Lucy's parents can assist financially, it is not always the case and represents juxtaposition for the sandwich generation caregiver who is not only caring for his wife, but also has a daughter finishing college.

[Spouse, EOD] *"I got a list of aging services with caregivers but you call (inaudible) and they're all busy. So I put an ad in the paper and I was very fortunate, this older lady, actually her grandson was one of my son's good friends*

in elementary school but um she had been a caregiver for a state senator's wife here for years who had Alzheimer's, and um. ...had experience, yea. And and these people, I figure she had good (inaudible) with these people. And um I interviewed a younger gal in her 40s who had three teenage boys; most of her experience was not in a home situation it was in a personal care home. ...I find myself getting a little resentful and start pleading, I appreciate your financial help and everything that you give us, and the kids and everything, but, but we can get by without that."

Interestingly, the spouse of the early-onset patient is savvy. Although his wife qualifies for no financial or social service supports, he has explored other alternatives. These alternatives include qualification for clinical research trials as a means of accessing medications and services. The early-onset patient is enrolled in a double-blind placebo controlled trial sponsored by a drug company. Unfortunately, one of the main barriers of clinical research trials is age.

[Spouse, EOD] *"So between that and the fact that she can't qualify for the trials because she doesn't do well enough on the tasks or she's not old enough, again, got to be 56 for most of them, it's frustrating. I unloaded on this guy, I said I don't understand it I said to me she's in perfect health other than the Alzheimer's...."*

5.2. BUILDING A SOCIAL SUPPORT NETWORK

An essential element to realizing a stable community dwelling status for the patient is the family caregiver's ability to build a social support network. This network includes family,

friends, and social groups that provide emotional support, physical assistance and respite. An element to building social support networks needs considered. For families of a late-onset Alzheimer's disease patient, elderly spouses, adult children and grandchildren become members of the social support network. For families of an early-onset Alzheimer's disease patient, aging parents, spouses and dependent children are members of the network. The dynamic and potential types of support in these differing networks results because of the age of onset for the disease.

The adult caregiving daughter of the late-onset patient described the support network in place for this family. She was asked if she had an emergency, and couldn't be here, couldn't give his medicine, what kind of back-up plan does she have. The following quotation is a response to this question.

[Daughter, LOD] *“Well my husband normally is home. Um, I have a cousin who lives next door. Like say for instance, (caregiver's husband) has guitar lessons on Wednesday night or is out of town, he comes over and he's there as a back-up. We have a lot of good family. Yeah, and my aunt... (can be instructed in the medication routine) Yeah, yeah. And, and I think that's very helpful with the pills being put out, or whatever, too, I mean, my husband watches the routine, my aunt knows the routine, you know, it's better to have more than one person know the routine. No doubt. But I think if something would seriously happen, like, God forbid, I got in a car accident or something, (sister who shares caregiving duties) would immediately take over. And same for me. You know, so we have each other to back us up.”*

In comparison, the spouse caregiver of the early-onset patient has difficulty establishing a social support network. Family support appears to be limited as does support by friends. In addition, this family caregiver struggles within this small network available to them. This couple has two adult children; a son working in California and the daughter, a fine arts major, went to Europe for the summer. The son is quite accomplished. "Everything he touches turns to gold." The husband is unhappy about the daughter's trip to Europe because he would rather have her home this summer to be with her mother. Moreover, the daughter is having difficulty handling the changes in her mother's condition and functional ability. The son, on the other hand, is extremely good and patient with his mother. The patient's siblings, two brothers, have both died at early ages due to an accident and cancer. The spouse of the early-onset patient has a small and limited network. Outside of his family, there is the in-home caregiver that stays with the patient three days a week and also a wife-nurse who assists with her care when this spouse takes trips to perform in a Civil War band. This spouse has a friend whose wife is a nurse and volunteers to assist with the care of the EOD on the Civil War band trips.

In contrast, the family of the late-onset patient has support, in addition to their family and friends, of those who care for their elderly father. This family has established strong connections with the outside caregivers; there is a line of communication and trust between all involved in the caring of this patient.

[Daughter, LOD] *"I can actually get his bag and show you, 'cause we, we um, have a little bag, um, that goes to and from the center that will [we use to] communicate. This is a little med bag (sound of bag unzipping) and all his meds come in here once a month. He, it's this thing here, (showing the researcher the*

notebook-journal) and it was happening once... Well, when something's goin' on, like they checked his ears and here's today. (Reading) "Saw Mr. S. today, and he has an irritation in both external ear canals, please apply ..." (Continuing to read) *"Also took new ear impressions today and changed the tubing ..."* oh, his hearing aids were broken... (continuing to read-backward in time) *But, so you'll see "had my flu shot today" But I charted it when he was having seizures [sound of pages turning]... 'cause we were tryin' to figure out, they were startin' to come more frequent, at least they ... they were happening once every three months. Here, April second was the first one, June couldn't pinpoint a day, August 29th, then by October into November he had like nine. And we were the only ones seein' them (seizures) at first, then the Center had seen it. Then the caregiver at his house while we were still working had seen it. Then we started getting' to the nitty-gritty a little bit as to what's goin' on. Dr. M thought it was cardiac, and then, you know, they did the 24-hour monitor on him, and ... stuff like that."*

[Spouse, EOD] *"We were in Virginia for one of my scheduled appearances and walking through the hotel lobby, (the patient) became uncontrollable and paranoid. We finally got her to her room and she settled down. She felt someone was after her and going to kill her. She was extremely upset. Many of the other men playing in the band have wives and they have pitched in to assist with (the patient) on these trips. One person in the band has a wife who is a nurse and she has been very good to (the patient). However, there is a trip coming up very soon and I will not take her on this trip because the nurse-wife will not be there."*

[Spouse, EOD] *“I have one group here in town who has offered me help at all and it’s called CareNet and it’s put together by the churches. Most of the help they give is like volunteer services for 2 or 3 hours. Which is not what I needed you know. But I do meet with one of the gals there (referring to CareNet) who is a nurse, really nice lady, we have coffee every once in a while and just chat. She got me to go to an Alzheimer’s support group at the hospital and I went. It was kind of interesting. Except nobody there is in my situation, they’re all there with parents. And and they’re older. They’re not keeping up on any research...Like somebody said you know, in Pittsburgh you have more access to services. It’s really frustrating. They’re diagnosing younger and younger.”*

5.3. MAINTAINING CONTINUITY OF CARE

‘Continuity of care’ becomes an aim for the family caregivers to achieve. For those families who are unable to succeed in ‘accessing social services’ and ‘building a social support network, continuity of care may not be attainable. Accessing social services and cultivating a social support network are essential conditions for attaining continuity of care. Necessary elements in continuity of care are communication between caregivers, normalization or routinization of care, and planning for emergencies. The caregiver of the late-onset patient provides the following description of their weekly routine.

[Daughter, LOD] *“The Community Life van comes for him and at that point, he is just taking his vitamins, and they pull up. So it’s really repetitive timing, especially during the week with how we do things. And I think that is important*

because it's routine. You know, it's that routine thing again. And it's better because of his medication to be around the same time, I don't really think a couple of hours makes a difference in the mornings that he sleeps in,...but nothings really different on the weekend, um as opposed to the weekdays. Yea. Pretty much the same."

In addition, these caregivers stress the importance of routine and the need to adjust behaviors to maintain the routine.

[Daughter, LOD] *"She's gonna pick you up." So everybody's in a routine and we just share that with home care, and they follow through real nicely, ...We have really been blessed with the situation."*

Chaos can erupt when continuity of care is not established. The importance of the routine of schedules was not seen in the family of the early-onset patient. This family caregiver, with a limited social support network and access to social services, struggles to manage his wife's care. In the following passage, the family caregiver describes the chaos that ensued when the patient's parents provided care to her. Considering the patient's parents do not provide consistent care to her, they are not properly prepared to provide her care.

[Spouse, EOD] *"Like we had a problem last weekend. She stayed with her parents and they came on Saturday afternoon to let the dog out. I had a job down in Washington I had to leave at 5:30 in the morning and didn't get back until 11*

so she stayed with her parents and they came in the middle of the afternoon and the dog had pooped in the house. First time it's ever happened. Well her mother and father got REALLY upset apparently. And swatted the dog and and (the patient) got REALLY upset."

In achieving 'continuity of care', families emphasize the importance of communication. Communication is essential to pass information to all caregivers involved, to control the behaviors and actions of those involved in the day to day care, and to achieve normalcy amongst the caregivers.

[Daughter, LOD] *"Oh yeah, we make sure that if something's not working, that we tell the other person, and then 90% of the time we realize it. Both of us have seen the same thing...And I'll say, "Well this works for me," and then she says, "Okay, I'll try it." Or I'll say, "He's startin' to do this," she says, "Yeah, I know he did it for me the last two days, try this." And we talk everyday just about, about dad. So, he's spoiled ... (laughing)"*

[Daughter, LOD] *"The internet, and Community Life. Yea, I do get information from them (referring to Community Life) although there's a lot of times that I've given them information, or you know, "Oh, I read this, what do you think about this" and then they'll run it past the doctor and um, she's pretty busy, so you almost have to call again, like if you feel real strong about something, but other than that, they're extremely good. "*

The final component of continuity of care is planning for emergencies. If the family caregiver's social support is not solid, they struggle to maintain normalcy in their own lives. In addition, with a small or limited social support network, the establishment of continuity of care is a delicate and conscious process.

[Spouse, EOD] *"The paid caregiver will come anytime we need her. She's real flexible. Right now we're doing 21 hours a week. If I need her to stay on a weekend with (the patient) she will. If I need an overnight, she will stay. She's real flexible that way. ...It is, and that's why I took her, that's one of the reasons I took her over the younger lady who has teenage kids."*

5.4. MANAGEMENT OF HEALTH CARE NEEDS BEYOND AD

An important component for the family in achieving a stable community dwelling status for the patient is to begin managing the health care needs beyond the patient's diagnosis of AD. The family caregivers of the late-onset patient have been able to succeed in the management of the diagnoses of AD. They now can place more of their focus onto the patient's (other/additional) health problems. The late-onset family provides an illustration of how they are able to manage Robert's health beyond the AD.

[Daughter, LOD] *"But he does see his... you see your cardiologist on Wednesday, and I'm gonna pick him up at the Center and take him there, um, because (laughing at something PT does) knock it off. They think it's cardiac. I think it's uh, I mean I've worked with people with handicaps for 12 years. ... Yea, he*

trembles, he goes (pause) you know... This was before; this was why we tried him on the Dilantin, cause I just think it's neurological. They put him on uh, they changed his Cardizem and put him on those two heart pills and he's still having the spells so we got him on the Dilantin and we didn't see one since we've taken him off either. So I'm, I know it's neurological, I mean he needs a cardiac appointment anyway. He had a quintuple bypass about 16 years ago, so he needs a cardiology appointment anyway, but I don't believe that it's cardiac, in my own mind anyway...I've seen too many seizures (laughing) to know that it's... you know, but uh..."

Unfortunately, the family caregiver of the early-onset patient has not been able to achieve this component and therefore, he continues to deal with the diagnosis of AD.

[Spouse, EOD] *"I mean, personality wise, most of the time she is just fine and you know. I notice that later in the evenings she seems to get real confused later in the evenings. She can't do a lot of tasks now as far as her memory stuff and that. But in the evenings she gets almost nonfunctional sometimes. Like last night we had a phone call and she was taking the portable phone and I asked her to bring me the phone. She tried to bring the whole unit out."*

[Spouse, EOD] *"...yea, I mean she was having a hard time with things, she couldn't even remember (inaudible - anything). She can have 3 pill bottles in front of her and take one and not remember she took it...short term memory is*

awful...long term memory is great. And I don't know whether that's typical or not. I think it is probably. We ran into some people in town at dinner a few weeks ago and that we'd just seen on a social basis, they're older, they're from Blairsville, and and they were having dinner and Sue and their daughter, like 35 years ago went to a church camp together. She asked them by name how the daughter was doing. It's just amazing."

6. DISCUSSION

This study documents and describes how family caregivers maneuver through a system to provide for their family member. The data provides two case exemplars which highlight the factors to achieving a stable community dwelling status for the patient. The analysis identified and described how these essential components facilitate this process. In addition to the elements, barriers and setbacks were identified. The objective and its components provide insight into the caregiving process which may be key to social policy revision.

Access to social services is a difficult hurdle. Medicare, Medicaid and Social Security Disability Insurance have defined eligibility criteria. And for those AD patient's who fall below the age requirements, live in communities or do not meet economic requirements, these programs fall short. These families struggle to achieve a stable community dwelling status for the patient. They may explore additional outlets, such as respite or extended family support, yet are likely to only receive minimal levels of support. Because family caregivers of AD patients need to continue working, as demonstrated by all three family caregivers in the cases studied here, these social services are essential to cover informal costs formal caregivers, such as adult day centers or in-home caregivers. These programs, Medicare, Medicaid, and Social Security Disability can afford family caregivers the ability to acquire this additional assistance. However, these policies are not available to patients and families of early-onset Alzheimer's disease. Informal cost associated with AD include incremental caregiver time required to assist

the patient with activities of daily living (ADLs), instrumental activities of daily living (IADLs) and supervision for patient safety.^{13, 14}

These families cultivate their established social support networks by coordinating care with other members of the AD patient's family, and enhancing their support networks with the formal caregivers, doctors, nurses, extended family and friends. Social support networks that are well developed can have a positive affect on the life of the patient.⁷² They are able to do this by providing consistency, familiarity, normalcy. It does not appear necessary to have a large social support network. Most important is a social support network that is informed, consistent and communicative with each other. In addition, the social support network must be trusted and reliable.⁷²

With the establishment of a strong social support network, continuity of care is fostered. As the social support network begins to work together, care becomes consistent. For those diagnosed with early-onset AD, continuity of care may be a challenge. It is difficult for families to accept such a diagnosis. In addition, it becomes a challenge for the primary caregiver to rely upon family members and friends. Therefore, the primary caregiver may have to resort to the assistance of outside caregiving services. Another challenge facing AD patients and family caregivers when emergencies arrive and these outside caregivers are unavailable and they then must rely on those family and friends to assist with the patient's care. Families of late-onset patients may have an advantage to maintaining continuity of care due to the fact this disease is perceived as disease of the elderly, they are adults who have stability in their own lives and the patient is eligible for a variety of benefits. The primary caregivers of late-onset patients may have an established social support network that can assist with the care of the AD patient. If the primary caregiver has siblings they may be able to rely upon to assist with care. This reflects the

trend that primary caregivers tend to be the spouse of the patient, live with the patient and continue to work relying upon formal (outside) caregivers.^{11, 14}

Each patient and family does not necessarily achieve each component in the process. They may, in fact, fluctuate between these elements. Much of this fluctuation is a result of the needs of the patient and caregiver. At any given time in this process, the patient may need to have their medical conditions monitored for illnesses other than the Alzheimer's disease. The primary caregivers must address these issues as they arise. It is a difficult balance for these patients and caregivers.

The family caregiver may have a better opportunity to provide for their AD patient if they are eligible for all social services. I suggest that for all patients with AD and their family caregivers to face this diagnosis on a level playing ground should be based upon diagnosis of disease instead. Although it may be argued that this would place an ever increasing burden on the cost of benefits such as Medicare, Medicaid and Social Security Disability Insurance, I would argue it would not be based on the shorter length of anticipated life expectancy of early-onset patients than those with late-onset^{42, 43}. At this time, the early-onset patients are not eligible for Medicare, Medicaid and Social Security Disability Insurance.^{58, 59, 62} Although the early-onset patient in this case was receiving Medicare and Social Security Disability Insurance, the receipt of these benefits was due to a previous psychological disability and not her age or diagnosis of AD. Furthermore, eligibility based upon diagnosis for early-onset patients and family caregivers would be beneficial in that families may be able to continue caring for the patient in the community.

6.1. PUBLIC HEALTH SIGNIFICANCE

Continuing to maintain care for Alzheimer's disease patients in the community setting is of great significance to the field of public health. Because those people diagnosed before the age of 65 face difficulties, financially and socially, altering the eligibility criteria for access to social services will aid in maintaining them in the community setting for longer periods of time.

- Federal government agencies, such as Medicare, Medicaid, and Social Security Disability Insurance, need to view early-onset disease with the same perspective as late-onset Alzheimer's disease, setting the precedent for state programs and allowing eligibility criteria to be based upon diagnosis.
- State agencies who monitor these programs need to view those younger than 65 with Alzheimer's disease in the same perspective as those with late-onset AD and begin to alter eligibility criteria for these benefits.
- Federal and state agencies should plan for additional sources of funding to enable the financial support to all persons diagnosed with Alzheimer's disease, whether late-onset or early-onset.
- Federal and state agencies should begin to discuss the impact the diagnosis has upon the health care system, specifically the fact that this population is expected to almost quadruple in size from 2001 to 2050.
- Social support organizations should provide resources and information based upon the needs of both families of late-onset and early-onset patients.

- Social support groups should provide counseling to early-onset families as a means to aid with coping, a result of a sometimes shocking and unbelievable diagnosis.

Although the results of this study may not be transferable to all Alzheimer's disease patients and their families, it provides insight into the struggles that patients and families may encounter as a part of the disease and accessing social care needs. The information gathered here can be used as a beginning step into further research to study the needs of these patients and families. In the end, this study adds to the body of knowledge regarding Alzheimer's disease patients and their families social care needs by detailing the experience of accessing social services, cultivating social support networks, maintaining continuity of care, and managing health care needs beyond the diagnosis of AD.

APPENDIX A



University of Pittsburgh
Institutional Review Board

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Exempt and Expedited Reviews

University of Pittsburgh FWA: 00006790
University of Pittsburgh Medical Center: FWA 00006735
Children's Hospital of Pittsburgh: FWA 00000600

TO: Dana DiVirgilio-Thomas

FROM: Sue R. Beers, Ph.D., Vice Chair 

DATE: July 31, 2006

PROTOCOL: The Impact of Social Policy on Alzheimer's Disease Patients and Their Family Caregivers

IRB Number: 0607055

The above-referenced protocol has been reviewed by the University of Pittsburgh Institutional Review Board. Based on the information provided in the IRB protocol, this project meets all the necessary criteria for an exemption, and is hereby designated as "exempt" under section 45 CFR 46.101(b)(4).

- If any modifications are made to this project, please submit an 'exempt modification' form to the IRB.
- Please advise the IRB when your project has been completed so that it may be officially terminated in the IRB database.
- This research study may be audited by the University of Pittsburgh Research Conduct and Compliance Office.

Approval Date: July 31, 2006

SRB:kh

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