Factors that influence decision-making for out-of-home placement of Alzheimer's disease patients by caregiver wives

Rebecca Ann Smith

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FACTORS THAT INFLUENCE DECISION-MAKING FOR OUT-OF-HOME PLACEMENT OF ALZHEIMER'S DISEASE PATIENTS BY CAREGIVER WIVES

A Project
Presented to the Faculty of California State University,
San Bernardino

In Partial Fulfillment of the Requirements for the Degree Master of Social Work

By

Rebecca Ann Smith

June 1998
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OUT-OF-HOME PLACEMENT OF ALZHEIMER'S DISEASE
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ABSTRACT

This study addressed the question "What influences the decision-making process for out-of-home placement of Alzheimer's diseased (AD) husbands by their caregiver wives?" The sample included 20 caregiver wives of AD patients who were from the Desert Valley Medical Group in Victorville. A perspective was used in which burden was viewed as the mediating force between the AD patient and the impact on the caregiver. Sixty-minute interviews were conducted with the participants. The interview followed the format of a questionnaire which applied the concept of subjective burden and objective burden. The subjective questions regarding the patient were interpreted by the caregiver and included cognitive incapacity, disruptive behavior, and lack of sociability. Impact variables of the caregiver included relationship changes. Included in the questionnaire was a cost of care index, and utilization of community resources. The findings indicated ten areas which approached significance. Further research is needed on impact of the couple's relationship.
ACKNOWLEDGEMENTS

I wish to thank my husband Buddy, for his constant encouragement, loving kindness, humor and understanding throughout my frustrations and late nights burning that midnight oil. Without you holding up my eyelids, I would never have finished!

I also wish to thank my friend, Mary Klein, for never giving up on me and providing me with a sense of sanity.
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INTRODUCTION

Alzheimer’s disease is a progressive disease which affects an estimated four million Americans and is the fourth leading cause of death among adults in the United States (Aronson, 1988). Caregivers of Alzheimer’s diseased (AD) patients are forced to adapt to constant changes, and problems. Often the patient’s behavior becomes bizarre, their personalities change, and at times, they become verbally and/or physically abusive.

A high level of strain is placed on spouses providing care for brain impaired partners with AD. Frail and elderly caregivers often isolate themselves due to the demanding 24-hour care needs of their loved one. The unlimited care needs and increased stress raise the risk of poor health for caregivers. Gender differences suggest women report more subjective stress and may feel emotionally constrained (Finley, 1989; Horowitz, 1985; Miller & Cafasson, 1992).

Many caregivers struggle with their commitment, values and dedication toward the ill spouse when he or she begins to need a higher level of care than the caregiver can provide. The physical and emotional demands of the caregiver often prompt eventual consideration for out of home placement. The caregiving spouse may react to this impending change with feelings of guilt or a sense of loss.
Older married couples in the cohort now elderly, often have strong values about commitment, family solidarity, and respect for each other. Due to their strong value system, letting go of caregiving responsibilities creates negative affects and a conflict of feelings, making the decision process for out of home placement more difficult.

Finances become a problem due to increased expenditures as the patient's medical needs continue to elevate, often over a course of many years. Frequently, fixed incomes eliminate the possibility of hiring needed help in the home. Out of home placement may create a financial hardship for the caregiver. The cost of institutionalization often exceeds $100.00 per day. Private pay couples can expect to spend down their assets and become dependent on Medi-Cal to supplement this expense (Korbin, 1989). Therefore, the caregiver must apply for financial assistance, creating additional conflict within the couple's value system. Other couples may not qualify for financial aid if their income is above the allowable limit. However, their income may still be too low to afford meeting this high expense.

This project focused on female caregivers that have reached an unplanned development in their lives. Their husbands were diagnosed with a progressive illness,
alzheimer's disease, which attacks the brain and results in impaired memory, thinking and behavior.

Previous research indicated underutilization of formal services by family caregivers (Gwyther, 1990). New service approaches are needed to help caregivers resolve the negative affects or conflicts which may effect their decision making process and hesitation to accept available help. The negative effects or conflicts needing attention include financial worries, lack of social support, the mental health of the caregiver, feelings of guilt or a sense of loss.

The goal of the research was to provide useful information on caregiver wives that would assist the clinician in developing preventive and intervention planning for these couples. The research data verified which of the various concerns viewed by caregiver's had the greatest impact on their decision making process when considering institutionalization.
Alzheimer’s Disease

The term dementia is used by the medical community to describe patients with impaired intellectual capacity. Dementia patients may also be labeled as having presenile or senile dementia, chronic or organic brain syndrome, arteriosclerosis, cerebral atrophy or senile dementia of the Alzheimer’s type (Krupp, 1986). It is important to point out that dementia is not a normal part of the aging process. Dementing conditions are caused by abnormal disease processes, and can affect younger as well as older persons (Cummings & Benson, 1983).

Alzheimer’s Disease (AD) is named after Alois Alzheimer (1864-1915), a German pathologist, who first identified the brain changes that occur in this disease (Dorland, 1967). The Social Work Dictionary defines Alzheimer’s Disease: “An organic mental disorder occurring most often in older people. Alzheimer’s disease is characterized by confusion, forgetfulness, mood swings, impaired cognition to learn, disorientation, and dementia” (Barker, 1995). It is thought to be the result of diffuse brain atrophy, especially in the frontal lobes. The nerve cells in the part of the brain that controls memory, thinking, and judgment are damaged, interrupting the passage of messages between
cells. Messages are passed between neurons by neurotransmitters. In AD patients, one specific neurotransmitter is lacking, and is believed to be the cause of the disease (Taylor, 1990). The cortex of the brain shrinks, causing less surface area in the brain, which plays some part in how well a person can think and function. The medical field views AD as a brain disease causing loss of recent memory, confusion and poor judgment. It is a type of chronic organic brain syndrome or dementia. It is a terminal illness that shortens one's expected life span (Gwyther, 1990).

According to the U.S. Congress, Office of Technology Assessment, an estimated 2.5 million to 6.5 million persons nationwide suffer from dementia (U.S. Congress, 1987). Approximately 4 million of these people are afflicted with AD according to the Alzheimer's Association (A.A., 1991). By the year 2000, the number of victims of severe dementia is expected to increase by 60 percent.

It is believed AD is not caused by normal aging, hardening of the arteries, mental retardation or mental laziness, or a vitamin deficiency (Gwyther, 1990). It is not caused as a direct result of stress, grief, neglect or family conflict, an emotional illness or a spiritual hex. It is not due to a lack of blood or oxygen to the brain, a
result of poisoning, a blow to the head, or chronic alcoholism. It is not preventable or curable.

Signs of dementia include short-term memory loss, inability to think problems through or complete complex tasks without step-by-step instructions, confusion, difficulty concentrating and paranoid, inappropriate or bizarre behavior (NIOA, 1980).

Possible causes of deteriorating intellectual capacity may be a variety of diseases and disorders. The National Institute on Aging states there are 100 conditions that mimic serious disorders, but are actually reversible. These are sometimes called pseudodementias, and are often treatable. Conditions causing reversible symptoms of dementia may include reactions to medications (Gilhooly, Zarit & Birren, 1986). Older persons taking more than one prescription drug may become confused. The most common drugs prescribed today are sedatives, hypnotics, and antiarthritic medications, which may cause dementia type symptoms. A doctor for possible side effects should monitor all medications, including over the counter drugs.

Another cause of AD symptoms may be emotional distress, such as depression or a major life change such as retirement, divorce or loss of a loved one. Problems including renal failure, liver failure, hypoglycemia,
hepatic diseases or pancreatic disorders can provoke a confusional state, as well as changes in sleep, appetite or emotions.

Undetected problems of vision or hearing may result in inappropriate responses. This could be misinterpreted as dementia because an individual is unable to perceive surroundings or understand conversations. Deficiencies of folate, niacin, riboflavin and thiamine can produce cognitive impairment.

Loss of taste and smell, loss of appetite, poorly fitting dentures or even difficulty shopping or preparing food may lead to nutritional deficiencies. Special attention should be given to people who have difficulty chewing, swallowing, or digesting food. Endocrine abnormalities such as hypothyroidism, hyperthyroidism, parathyroid disturbances or adrenal abnormalities can cause confusion which mimic dementia.

Infections in older persons can produce a sudden onset of a confusional state. Blood clots on the surface of the brain can form which create collections of fluid that create pressure on the brain. These clots can be treated by draining the fluid before it causes permanent damage.

Brain tumors can cause mental deterioration. Benign tumors can be surgically removed. Other tumors may be
treated with a combination of brain surgery and radiation/chemotherapy.

To diagnose dementia, a complete medical and neuropsychological evaluation is needed (U.S. Dept. of Health & Human Services, 1993). Brain scans such as CT or MRI are an important part of the process. The diagnostic procedure is a process of elimination to rule out any treatable causes of dementia. In many cases, a definite diagnosis is not possible until after an autopsy can be performed.

Progression

Individuals with AD become progressively impaired in their abilities (Aronson, Miriam, 1988). Symptoms such as memory loss, disorientation, and changes in visual and spatial perception may result in persons getting lost, and having slowed reaction times. While persons with early dementia may not seem to have these problems, eventually motor coordination, powers of concentration, and exercise of appropriate judgment may become affected by the disease.

Caregivers, in the beginning, are confused by the behavior of their partner. The spouse notices forgetfulness, personality changes, and other odd behavior. The first stage symptoms may include memory loss which affects job performance. The AD patient may get lost or confused about
where they are. Their spark for life may decrease. A loss of initiative and moodiness is notable. Poor judgment results in bad decision-making and routine chores take longer. Handling money and paying bills become difficult.

The second stage is the longest, normally lasting between 2 to 10 years. Symptoms include increasing memory loss and confusion, and a short attention span. Close friends and family begins to recognize problems. The patient makes repetitive statements, is restless, and demonstrates perceptual motor problems (Gwyther, 1990). Occasional muscle twitches or jerking may occur. The patient has difficulty organizing thoughts, and can't find the right words. He makes up stories to fill in the blanks. Problems develop with reading and writing numbers. He may become suspicious, irritable, fidgety, teary or silly. It is during this stage that a loss of impulse control becomes evident. The patient becomes sloppy, won't bathe or is afraid to bathe, and has trouble dressing. Weight gain or weight loss often occurs, and he may see or hear things that are not there (US Congress, 1987). Ideas often become fixed or unreal. Now he needs full-time supervision.

By the time the patient is diagnosed with AD, the caregiver has already undergone considerable strain (Boss, Carron, & Horbal, 1988). During the time the patient is
first deteriorating, the caregiver has assumed primary responsibility for his care. As the patient becomes increasingly difficult to care for, the caregiver complains about the patient to other family members. At first, family members try to be understanding and helpful. Eventually they may think that she is exaggerating or simply not trying hard enough to cope. Conversations between the caregiver and family members may deteriorate. It is often this breakdown in support that creates oppressive and unrelenting stress that may obstruct established coping patterns of a previously well functioning family (Deimling & Bass, 1986).

Each member of the family is affected by Alzheimer’s Disease, not just the primary caregiver. For example, the adult children can be very concerned if they see the caregiver, which is supposedly well, deteriorating in the process of caring for the patient. The adult children may also feel that the disease has genetic implications for themselves, or fear they may cause the patient’s behavioral outbursts (Gwyther, 1986).

There is a sharp sex division in who takes care of old people when they are sick (Johnson & Catalano, 1981). This is generally due to the fact that in people now old, husbands are older than their wives who have a longer life expectancy. Men are more likely to remarry than are women.
Most older men, 37%, when sick, are cared for by a wife. Most older women, 29%, are cared for by a daughter (CRC, 1994). Husbands provide care to their wives in 14% of cases, sons provide 6%, parents 5%, siblings 3% and others 6%. When a husband is discharged from an acute care hospital, the services the wife renders tend to be more lasting and more comprehensive.

Commitment to the spouse, in the cohort now old, is still predominately "for better or worse" (Johnson & Catalano, 1981). This commitment is a joint one. Older couples become interdependent at the end of life. This includes nursing of each other and dividing up household chores based on abilities. It was noted in a study by Johnson and Catalano (1981) that the spouse, who took care of the other, was likely to be in poor health. Women would more likely feel burdened by caregiving than men would. Women are most likely to do most of the work, where as men tend to use available community resources.

Due to the progressive nature of this dementia, unique coping skills are required and additional demands are made upon caregivers. Among long term marital partners, the wife must continually change what is expected of her. She may be threatened by the expectation of a separate future. Letting go may be the beginning of a prolonged period of
anticipatory grief and bereavement (Gwyther, 1990). Feelings of abandonment or irreparable loss can surface causing wives to become protective of the marital relationship when having to share care of the patient (Gwyther, 1990). This may cause greater anxiety and stress than when their husband does not recognize them. Asking for help could be an acknowledgment of the potential of becoming a single woman.

A major task in late life is adaptation to the impact on self of multiple losses and loss of object constancy (McCaslin, 1987). Unexpected changes can occur in rapid succession and overwhelm an elderly person whose basic physiological ability to deal with stress is reduced. It is during this time that symbiotic attachment issues from earlier child and parent relations can surface. The elderly caregiver may respond by regressing to a range of primitive defenses with which to cope. This late life stress may explain the tendency of the old to somatize and the prevalence of hypochondria (McCaslin, 1987). Caregivers may withdraw socially as a defense mechanism. Somatization, physical illness, and affective disorders can mask depression. Some studies cite denial as a major defense in recognizing aging and death. In contrast, other research
shows older people using denial as a realistic response to loss, and as an adaptive mechanism.

Separation-individuation conflict has been used as a conceptual framework for understanding late-life conflicts centered around caregiving (Lewin, & Lundervold, 1990). The caregiver may have set a self-rule that "Only I can provide adequate care for my husband." "I must provide all of the care." This is dysfunctional in the sense that by following this rule, the caregiver never takes time off from caregiving. In fact, she will not use respite care and suffers from fatigue, depression, burden, and stress (Lewin, & Lundervold, 1990). The caregiver's behaviors toward the AD patient might be under dual control of the nonverbal and verbal antecedents and consequences of others and the beliefs or rules that have been adopted by the caregiver.

Conflicts surrounding the need for newer resolutions of separation-individuation issues may affect decision making and the reluctance to use available help among older caregivers (Gwyther, 1990). This conflict may stem from feelings and values. Older couples today may feel more or less subjectively constrained or stressed by the adaptional demands of caregiving, but they seem to behave on the basis of well-established values about commitment and family
solidarity. In order to respect themselves, older caregivers may have to live up to their values. This is because the losses associated with honoring these values generate uncomfortable feelings (Gwyther, 1990).

Caregiver Burden

Caring for an AD husband takes a heavy toll on the caregiver. The caregiver experiences considerable stress and 50% of them meet the criteria for a diagnosis of depression (Gallagher, Rose, Rivera, et al, 1989a).

A study by Shields (1992) assessed caregivers of AD patients and depression. The findings indicated negative affective responses between the caregiver and other family members related to level of depressive symptoms in the caregiver. Negative affective responses by family members were shown to lead to major psychiatric disorders in the caregiver. In fact, family support and visits have been found to reduce caregiver stress and depression (Zarit, Reever, & Bach-Peterson, 1980; Zarit & Zarit, 1982). The family needs to be willing to give the caregiver time to talk about the difficulties they are experiencing. Shields also reported women caregivers have a higher level of depressive symptoms than male caregivers.

Studies have shown that some caregivers find caregiving to be burdensome and stressful (Cicerelli, 1981; Horowitz &
Dobrof, 1982, Robinson & Thurnher, 1979), while others find self-satisfaction from caregiving. For many, this time of taking care of a loved one is a treasured time of sharing, a time to express love through tenderness, patience and understanding. But it can also be the backbreaking work of lifting, bending, turning, and cleaning soiled bedclothes and linens. For many, this strength deepens the commitment of the caregiver and the AD husband. For some it is a time of pain, struggle, and exhaustion that may stretch to the breaking point in their capacity to care (Glasse, 1991). Montgomery, Gonyea and Hooyman (1985) did a study on caregiver burden by separating subjective burden (feelings, attitudes & emotions) and objective burden (events, happenings & activities). They found different factors predict each type of burden. Subjective burden related to characteristics of caregiver, and was not likely to be reduced by intervention. Objective burden was related to the type of caregiving tasks performed. Tasks that were found to restrict the caregiver in terms of time schedules or geographic location were found to best predict objective burden. Intervention for objective burden proved effective.

Caregivers frequently carry the burden alone. House bound and isolated, often depressed, financially depleted, they may abuse the AD patient, or become ill themselves.
(Glasse, 1991). Among the 1.6 million women caregivers, almost half, (44%) report they are in fair or poor health. Caregivers report an average of 93 hours of informal care per week to their impaired spouse (CRC, 1994). More than one in four caregivers, (27%) report that they get no help at all from family and friends (CRC, 1994).

High scores of caregiver burden are related to high levels of mental impairment in the AD patient. Deimling & Bass (1986) addressed this relationship of the AD patient in families providing high level of care. Symptoms were identified in mental impairment in the AD patient as being multidimensional in nature. These dimensions included social function, the presence of disruptive behaviors, and cognitive incapacity. This study measured the stress experienced by the caregiver in these three dimensions. The results indicated that the loss of social functioning has a more important influence on caregiver stress than the cognitive impairment of the AD patient. Cognitive incapacity was viewed as primary in generating other symptoms of mental impairment such as disruptive behavior and lack of social functioning. These symptoms were conceptualized as related to caregiver stress.

In applying this theory to the caregiver's physical health, the strongest direct effect was produced by the AD
patient's activities of daily living limitations. The higher level of care provided to the AD patient, the more likely the caregiver was to report change in their own physical health (Deimling & Bass, 1986).

Daily living limitations were studied by Kinney and Stephens. They developed a caregiving hassles scale to assess the daily nuisances of caregiving (1989). This scale, completed by caregivers of AD patients, focused on the patient's needs in relation to activities of daily living (ADL's), cognitive status, behavior, and on caregivers' social network (1989). The results indicated AD patients with more physical impairments created more hassles for the caregiver. Caregivers, who reported AD patients demonstrating more irresponsible behaviors, reported more hassles in dealing with the patient's behavior. Caregivers at the high end of the hassle scale reported higher stress levels.

Haley, Levine, Brown & Bartolucci (1987) researched measures of stress in the caregiver. The results were generally consistent with past research (Pagel et al., 1985; Zarit et al., 1980). A particularly striking result in the data was a weakness in the relation between the severity of objective caregiving stressors and caregiver outcomes. It was reported that life satisfactions and health of the
caregiver had a higher impact in contributing to depression than did the severity of the disease itself.

The greater use of coping mechanisms of logical analysis, information seeking, problem solving and affective regulation were related to higher self-reported health (Haley, Levine, Brown & Bartolucci, 1987). Also, higher levels of social support, and activity related to better health outcomes.

Suzanne C. Ouellette Kobasa, associate professor of psychology at the City University of New York Graduate School has studied personality characteristics. In her study, she contends there is a relationship between personality characteristics and coping skills. Her study focused on three components in coping skills, commitment, control, and challenge. Her study determined women often cope better than men do. Kobasa stated that if people are committed to who and what they are, what they do, and how they got into the predicament they are in, they deal with it. This takes cognitive flexibility as life presents us with unexpected problems.

One such unexpected life problem for caregivers includes providing a safe home environment for the AD patient. (Lach, Reed, Smith & Carr, 1995). The progressive loss of memory, judgment, and motor functions may lead to
hazardous behavior, resulting in accidents or injuries. The
once safe home now has a variety of new dilemmas. Among the
problems are falls, wandering, unsafe driving, and physical
violence that have long been reported in the study of
behavioral problems in AD. The issue of predicting when
safety problems are likely to occur for persons with AD is
unresolved. Safety problems are an important issue in
caring for AD patients. Family often underreports safety
problems or accidents that reflect poorly on their
caregiving ability (Lach, Reed, Smith, Carr, 1995).
Caregivers may not be aware of the potential safety problems
in the home. Physicians often recommend out of home
placement due to the impact and safety issues for the
caregiver.

In an effort to relieve caregiver burden, and promote
safe in home environments, Regional Resource Centers were
developed. California was the first state in the nation to recognize caregiver needs. Regional Resource Centers (RRC)
were designed to address these specific needs, especially when the patient's impairment is severe and untreatable
(Friss, 1990). Services may be provided directly to families by RRC staff or through the establishment of
service contracts with professionals and agencies in the community. RRC professionals were found to be the number
one need of families as a single source for information, advice, referral, and resource materials. Their assessments identify and record problem areas and assist in determining the most appropriate type of mix of services to meet the caregiving need.

RRC also offers consultation and planning for caregivers through steps to resolve problems or cope with unresolvable concerns. Counseling is provided to offer emotional support and mental health intervention to assist the caregivers in problem solving and long term resolutions in psychosocial issues related to caregiving.

Although respite care is offered by RRC, a 12-month study of families showed it was ineffective for caregiver burden and mental health (Lawton, Brody, & Saperstein, 1989). Often, due to the high need for RRC services, families must go on a waiting list for as long as two years. RRC also reported more than one in four caregivers, 27%, report that they get no help at all from family and friends in caring for the AD patient (CRC, 1994). Among those caregivers completing a comprehensive assessment, fully 66% show clinical symptoms of depression. Caregivers reported needing service assistance in respite care, visiting nurses, supportive services, and family help. Often financial assistance becomes a necessity.
An understanding of the financial burden of caregivers of AD patients is important since it has already been well documented that financial crises can result in stress on the caregiver (Todtman, Gustafson, 1992). Research has shown that economic stress is related to mental health and functioning. Strains on financial resources can result in depression, marital tension, family disputes, and psychophysiological distress (Todtman & Gustafson, 1992). For many caregivers, these costs have reached catastrophic proportions. What makes AD victims and caregivers particularly vulnerable to financial burden is that public and private insurance mechanisms are ill-designed to act as a safety net for the financial risks that are associated with AD (Who Can Afford, 1988).

Approximately 25% of the estimated $40 billion spent on AD patients annually is paid by state and federal governments; the remaining 75% ($30 billion) is paid by the victims and their families (Gonzalez-Lima & Gonzalez-Lima, 1987). Because of the nature of the disease, victims of AD require long-term care. In terms of finances, long-term care is potentially a catastrophic event for the victims and their families. Families have reported that they have paid heavy taxes and continue to do so with the new Medicare rates that do not provide long-term care. Many feel
Medicare is worthless to AD sufferers. Finances are a major worry. Caregivers are afraid that they will not be able to afford both nursing home costs and the caregiver's living costs. Many caregivers worked for years while raising children in order to accumulate a decent retirement income. With escalating costs of medical care, all of that effort is viewed as lost. Many caregivers can not get help to care for their husbands until all of their savings are used up. Frequently they perceive the idea that families with AD patient's deed their savings to their children in order to qualify for government help, while others had to spend everything, leaving the remaining spouse impoverished. Frequently caregivers will resist out of home placement as long as savings last. When all the money is gone they begin to sell their belongings or their homes in order to prevent institutionalization.

The risk of becoming financially destitute following institutionalization or after paying for home care, reaches alarmingly far into the general population of older people living at home in communities (Branch, Friedman, Cohen, Smith, Socholitzky, 1989). It is estimated that for each nursing home resident, another 2 or 3 elderly people living in the community share equal levels of dependency. In
comparison as many as 2.8 million elderly persons are at immediate risk of costly nursing home care.

Findings in a study by Lund, Pett, & Castera (1989) reflected caregivers as influenced by several interrelated factors when considering out of home placement. These factors included characteristics of the caregivers, their relationship with the AD patient, and the level of impairment. Anticipated institutionalization was greater if the patients were older, their impairment had progressed rapidly, and had rendered them more dysfunctional. The likelihood of institutionalization was also greater if the caregiver perceived more burdens, and their relationship with the AD patient was less close. This research also found that caregivers wanted to avoid premature or early institutionalization at almost any cost, but indicated that there is probably some time when it will be inevitable.

In reviewing these studies, it seems that there is a great need in understanding the decision making process in order to provide the necessary intervention.
RESEARCH DESIGN AND METHOD

Sampling

The population source for the study of AD caregivers was the Desert Valley Medical Group. The criteria for the sample were that of elderly married couples, living together where the wife was providing care for her husband with a diagnosis of AD. The agency provided a list consisting of 47 patients diagnosed with AD. A review of the patient charts was conducted by random selection. The primary sampling unit element included a male with AD and his caregiver wife. The secondary sampling unit was the bottom age limit of 65 years old. The final sampling unit was the couples were living alone in their own residence.

Phone calls were made to the homes giving a brief description of the study, and requested participation. Follow-up letters (Appendix B) confirming participation and appointment times were sent to the homes. Twenty of the 47 couples consented to voluntary participation.

The student researcher conducted individual interviews. The face to face interviews lasted approximately 60 minutes in the couples’ home, at times convenient for them. The researcher strictly adhered to the format outlined in the
questionnaire, which consisted of qualitative and quantitative questions.

Instrument and Data Collection

Sociodemographics of the caregiver was collected which included age, ethnicity, employment status, annual household income, education and current personal health. Sociodemographics of the patient included age, and ethnicity.

The mental impairment of the AD patient has considerable potential for the creation of burden and impact on caregivers. The concept caregiver burden was viewed as the mediating force between the AD patient impairments, and the impact that caregiving has on the life of the caregiver. In answering the research question, this study used measures originated from a sixty-two item questionnaire developed by Poulshock and Deimling (1984) (Appendix A). The measurements of AD patients' impairment in the larger instrument included Sociability, Disruptive Behavior, Cognitive Capacity, Relationship Changes, Impact on Social Support, Cost of Care, and Community Resources. This instrument utilized items rated on a Likert type scale.

For this study five dimensions of mental impairment from the Poulshock & Deimling instrument were used (Appendix A). Those measures had been derived from twenty-three separate items in a factor analytic model. The first
factor, Sociability, contained eight items showing patient level of cooperativeness, withdrawal, and isolation. A low score on this indicator represented a lack of sociability. The second factor, Disruptive Behavior contained seven items. This area focused on the patient’s acting out, such as striking the caregiver, swearing, and disrupting meals. The third factor, Cognitive Incapacity, contained eight items that measured the more traditionally assessed aspects of mental impairment such as forgetfulness and confusion.

Two impact measures were used for the fourth and fifth factors, Impact on Relationships and Impact on Social Support. For this analysis, 17 items were selected for the factor solution. Focus was placed on items chosen to represent impact that were constructed using relatively unidimensional elements that assess the impact caregiving has on various aspects of caregivers’ daily lives. These items include the impact caregiving has on family relationships, social, group and recreational activities, health, or employment changes.

Items from a Cost of Care Index instrument developed by Kosberg & Cairl (1986) were also included. Four of the twenty questions were incorporated into the research questionnaire to assist in the examination of the financial components, which have a relationship with caregiver burden.
A six-item community resource inventory developed for this study was added to provide information that related to services used.

Qualitative Analysis/Dependent Variable

Caregivers were asked three open-ended questions: (1) Their thoughts regarding placing their husband in a nursing home, (2) What things do you need help with, and (3) Who provided them with help. Question one provided the dependent variable placement.

To analyze these data, for question 1, caregivers that answered they had thought of placement for their husband scored a 1 for yes, and caregivers that answered no, or refused placement were scored 2. Question 2, if the caregiver indicated some type of help was needed a score 1 was given. If no help was needed, the question was scored 2. Question 3, if the caregiver had help from family, friend, or hired help the question was scored 1, and if the caregiver did not have help was scored 2.

The qualitative data in this study was obtained toward the end of the interview session. Time was allowed for additional comments and ideas from the caregivers.

Human Subjects

To maintain confidentiality and anonymity of the participants, personal names were not collected on the
completed questionnaires. A document labeled Informed Consent (See Appendix C) constituted the front page of the questionnaires. This form described the purpose, procedure, and the risk and benefit of participating in the study. The form included a request for the signature of the participant as giving her consent to participate and designated her understanding of the purpose, risk and benefit of the participation.

Upon completion of the interview and questionnaire, each was assigned an identification number for the purpose of rechecking coded data entries if it was deemed necessary. The informed consent sheets were removed from the completed questionnaire and maintained in a separate file.

At the end of the interview, through separate documentation, a Debriefing Statement was signed by the participants (See appendix D). It included information regarding whom to contact about the project if the participants wanted to talk about any aspect of the survey.

The only known risk factor was possible heightened awareness of need for assistance and of resources available within the community. A resource list was left in the participant’s home for them to use at their own discretion.

Strengths and Weaknesses
participation would jeopardize their eligibility for health insurance coverage at Desert Valley Medical Group. The researcher was able to personally reassure caregivers of their continued medical benefits, regardless of their participation in the research project. At times, the researcher provided clarification of a question. This created an honest, genuine atmosphere for obtaining accurate information.
RESULTS

Caregiver Characteristics

Forty-seven caregivers met the criteria to participate. Of those, 20 were randomly selected and voluntarily completed the questionnaires, yielding a 100% response rate.

Caregiver age ranged from 65 to 102 years old with the mean age of 77. Ethnicity of the caregiver included nine Caucasians, four African Americans, one Mexican American, two American Indians, two Asian/Pacific Islanders, and two others (Table 1). The highest percentage was the ethnic group of Caucasians at 45%, almost half of the population studied.

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caucasian</td>
<td>9</td>
<td>45.</td>
</tr>
<tr>
<td>African American</td>
<td>4</td>
<td>20.</td>
</tr>
<tr>
<td>Mexican American</td>
<td>1</td>
<td>5.</td>
</tr>
<tr>
<td>American Indian</td>
<td>2</td>
<td>10.</td>
</tr>
<tr>
<td>Asian/Pacific Is.</td>
<td>2</td>
<td>10.</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>10.</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
<td>100.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Status</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full-time</td>
<td>2</td>
<td>10.</td>
</tr>
<tr>
<td>Part-time</td>
<td>3</td>
<td>15.</td>
</tr>
<tr>
<td>Not employed</td>
<td>2</td>
<td>10.</td>
</tr>
<tr>
<td>Retired</td>
<td>13</td>
<td>65.</td>
</tr>
<tr>
<td>Total</td>
<td>N=20</td>
<td>100.</td>
</tr>
</tbody>
</table>

30
Employment Status

As to employment status, two respondents worked full-time and three part-time; one was not employed, and 14 were retired. This indicates 75% of the sample study were either unemployed or retired (Table 2).

Annual Household Income

Respondents' annual household incomes ranged from $10,000-$14,999, to over $20,000. No one reported an annual income below $9,999. The frequency indicates one half of the participants had an annual income of less than $20,000 or less. Fifty percent of the participants reported an income above $20,000 annually (Table 3).

<table>
<thead>
<tr>
<th>Income</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>$ 9,999</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>$10,000 - $14,999</td>
<td>4</td>
<td>20.</td>
</tr>
<tr>
<td>$15,000 - $19,999</td>
<td>6</td>
<td>30.</td>
</tr>
<tr>
<td>$20,000 - above</td>
<td>10</td>
<td>50.</td>
</tr>
<tr>
<td>Total</td>
<td>N=20</td>
<td>100.</td>
</tr>
</tbody>
</table>

Education

The caregiver level of education frequency indicates seven did not graduate from high school, six were high school graduates, and seven attended colleges. This indicates over 1/3 of the population did not complete the 12 grade (Table 4).
Table 4. Education

<table>
<thead>
<tr>
<th>Status</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not High School Grad</td>
<td>7</td>
<td>35.</td>
</tr>
<tr>
<td>Graduated High School</td>
<td>6</td>
<td>30.</td>
</tr>
<tr>
<td>College</td>
<td>7</td>
<td>35.</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>N=20</strong></td>
<td></td>
</tr>
</tbody>
</table>

Caregiver Personal Health

The caregivers rated their current personal health as excellent (5), good (5), fair (6), or poor (4) (Table 5). The frequencies indicate 50% of the caregivers rated their health as excellent or good, and 50% rate their health as fair or poor.

Table 5. Caregiver Personal Health

<table>
<thead>
<tr>
<th>Status</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excellent</td>
<td>5</td>
<td>25.</td>
</tr>
<tr>
<td>Good</td>
<td>5</td>
<td>25.</td>
</tr>
<tr>
<td>Fair</td>
<td>6</td>
<td>30.</td>
</tr>
<tr>
<td>Poor</td>
<td>4</td>
<td>20.</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>N=20</strong></td>
<td><strong>100.</strong></td>
</tr>
</tbody>
</table>

Patient Characteristics

Patient ages ranged from 65 to 93 years with a mean age of 76. The ethnicity of the AD patients included eleven Caucasians, five African Americans, one Mexican American, two American Indians, no Asian/Pacific Islanders, and one other (Table 6). More than half in the sample study were Caucasian.
Table 6. Sociodemographics of the Patient

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caucasian</td>
<td>11</td>
<td>55</td>
</tr>
<tr>
<td>African American</td>
<td>5</td>
<td>25</td>
</tr>
<tr>
<td>Mexican American</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>American Indian</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Asian/Pacific Is.</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>N=20</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

Sociability

The hypothesis proposed that there would be an association between sociability of the patient and out of the home placement. This category factors the AD patient level of cooperativeness, withdrawal and isolation. Low scores indicate a lack of sociability. The specific independent variables included in this category were interesting, enjoyable, friendly, interested, cooperative, clean, grateful and withdrawn (Table 7). Frequency tabulations showed that 55% of the patients were not interesting, 50% of the patients were not enjoyable to be with, and 55% were not cooperative. This reflects the negative changes in elder-caregiver and caregiver-family relationships.
Table 7. Sociability

<table>
<thead>
<tr>
<th>Interestingly</th>
<th>Enjoyably</th>
<th>Friendliness</th>
<th>Interoperable</th>
<th>Cooperative</th>
<th>Cleanliness</th>
<th>Gratefulness</th>
<th>Withdrawn</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Scale</strong></td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td><strong>SA</strong></td>
<td>10</td>
<td>10</td>
<td>30</td>
<td>10</td>
<td>10</td>
<td>10</td>
<td>15</td>
</tr>
<tr>
<td><strong>A</strong></td>
<td>45</td>
<td>50</td>
<td>25</td>
<td>25</td>
<td>45</td>
<td>30</td>
<td>25</td>
</tr>
<tr>
<td><strong>D</strong></td>
<td>10</td>
<td>30</td>
<td>15</td>
<td>25</td>
<td>15</td>
<td>20</td>
<td>20</td>
</tr>
<tr>
<td><strong>SD</strong></td>
<td>30</td>
<td>10</td>
<td>30</td>
<td>35</td>
<td>30</td>
<td>25</td>
<td>25</td>
</tr>
<tr>
<td><strong>DK</strong></td>
<td>5</td>
<td>0</td>
<td>0</td>
<td>5</td>
<td>0</td>
<td>5</td>
<td>15</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
</tr>
</tbody>
</table>

Disruptive Behavior

Disruptive Behavior variables focused on the AD patients' acting out, such as striking family members, swearing, and disrupting meals. The scores for items of complaints, lack of privacy, and disrupt meals rate the highest frequency (Table 8). Frequency tabulations showed that 45% of the patients complained, and 55% of the patients were embarrassing. These represent the restrictions in caregivers' activities resulting from caregiving.

Table 8. Disruptive Behavior

<table>
<thead>
<tr>
<th>Complain</th>
<th>Interferes</th>
<th>Privacy</th>
<th>Yells</th>
<th>Embarrassing</th>
<th>Disrupts</th>
<th>Strikes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Scale</strong></td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td><strong>SA</strong></td>
<td>20</td>
<td>15</td>
<td>20</td>
<td>10</td>
<td>15</td>
<td>20</td>
</tr>
<tr>
<td><strong>A</strong></td>
<td>45</td>
<td>30</td>
<td>25</td>
<td>25</td>
<td>55</td>
<td>35</td>
</tr>
<tr>
<td><strong>D</strong></td>
<td>20</td>
<td>35</td>
<td>35</td>
<td>35</td>
<td>15</td>
<td>30</td>
</tr>
<tr>
<td><strong>SD</strong></td>
<td>15</td>
<td>15</td>
<td>15</td>
<td>25</td>
<td>5</td>
<td>15</td>
</tr>
<tr>
<td><strong>DK</strong></td>
<td>0</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>10</td>
<td>0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
</tr>
</tbody>
</table>

Cognitive Incapacity

Cognitive Incapacity measured the more traditionally assessed aspects of mental impairment such as forgetfulness.
and confusion (Table 9). Frequency tabulations showed that 50% of the patients had three or more symptoms of cognitive incapacity.

### Table 9. Cognitive Incapacity

<table>
<thead>
<tr>
<th></th>
<th>Confused</th>
<th>Forgetful</th>
<th>Hears</th>
<th>Wanders</th>
<th>Fears</th>
<th>Mumbles</th>
<th>Repeats</th>
<th>Harmful</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scale</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>SA</td>
<td>50</td>
<td>65</td>
<td>25</td>
<td>45</td>
<td>30</td>
<td>30</td>
<td>50</td>
<td>15</td>
</tr>
<tr>
<td>A</td>
<td>25</td>
<td>25</td>
<td>15</td>
<td>45</td>
<td>25</td>
<td>40</td>
<td>35</td>
<td>15</td>
</tr>
<tr>
<td>D</td>
<td>15</td>
<td>5</td>
<td>35</td>
<td>0</td>
<td>30</td>
<td>10</td>
<td>5</td>
<td>35</td>
</tr>
<tr>
<td>SD</td>
<td>0</td>
<td>0</td>
<td>20</td>
<td>0</td>
<td>10</td>
<td>10</td>
<td>5</td>
<td>20</td>
</tr>
<tr>
<td>DK</td>
<td>10</td>
<td>5</td>
<td>5</td>
<td>10</td>
<td>5</td>
<td>10</td>
<td>5</td>
<td>15</td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
</tr>
</tbody>
</table>

Impact on Relationship

Two impact measures were used in which caregivers indicated that because of caregiving, or since caregiving began, specific aspects of family life were altered or affected. The topics included family relationships, and social, group, and recreational activities. These items measured negative changes in the caregiver, patient, and family relationships. The results show 30% of the caregivers were depressed and wished they had a better relationship with their husband (Table 10).

### Table 10. Impact on Relationship

<table>
<thead>
<tr>
<th></th>
<th>Angry</th>
<th>Depressed</th>
<th>Strained</th>
<th>Resentful</th>
<th>Manipulative</th>
<th>Better</th>
<th>Pleasure Requests</th>
<th>Depends</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scale</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>SA</td>
<td>0</td>
<td>30</td>
<td>15</td>
<td>15</td>
<td>15</td>
<td>10</td>
<td>35</td>
<td>20</td>
</tr>
<tr>
<td>A</td>
<td>35</td>
<td>30</td>
<td>25</td>
<td>30</td>
<td>30</td>
<td>15</td>
<td>25</td>
<td>20</td>
</tr>
<tr>
<td>D</td>
<td>30</td>
<td>10</td>
<td>25</td>
<td>35</td>
<td>37</td>
<td>20</td>
<td>25</td>
<td>20</td>
</tr>
<tr>
<td>SD</td>
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<td>20</td>
<td>25</td>
<td>15</td>
<td>20</td>
<td>25</td>
<td>25</td>
<td>20</td>
</tr>
<tr>
<td>DK</td>
<td>15</td>
<td>10</td>
<td>10</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>20</td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
</tr>
</tbody>
</table>
Impact on Social Support

The impact of social support questions are representative of restrictions placed on the caregiver’s activities by caregiving. More than 60% of the caregivers reported two or more areas of restrictions in their activities due to caregiving (Table 11).

<table>
<thead>
<tr>
<th>Table 11. Impact on Social Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group Theater Family Volunteer So.Life Time Church Activities</td>
</tr>
<tr>
<td>Scale % % % % % % % % % % % %</td>
</tr>
<tr>
<td>A 40 30 20 35 40 50 40 30 40 30 40 30</td>
</tr>
<tr>
<td>SA 35 15 40 35 15 15 25 40 30 10</td>
</tr>
<tr>
<td>D 15 30 25 5 25 25 30 10</td>
</tr>
<tr>
<td>SD 5 20 15 20 20 5 5 10</td>
</tr>
<tr>
<td>5 5 5 5 5 5 5 0 0 0</td>
</tr>
<tr>
<td>Total 100 100 100 100 100 100 100 100 100 100 100 100</td>
</tr>
</tbody>
</table>

Cost of Care Index

The cost of care index measured economical restrictions perceived by the caregiver. On the first question, whether caring for their husband caused them to dip into savings meant for other things, 35% strongly agreed, 15% agreed, 30% disagreed, 15% strongly disagreed, and 5% did not know. On the second question, “I feel that we must give up necessities because of the expense to care for my husband” 40% strongly agreed, 25% agreed, 20% disagreed, 10% strongly disagreed, and 5% did not know. Question number three asked if the couple could not afford extras because of the expense of caring for the patient. Fifty percent strongly
agreed, 25% agreed, 25% disagreed, 0% strongly disagreed, and 0% did not know. The final question was if the caregiver felt caring for her husband was too expensive. Sixty percent strongly agreed, 10% agreed, 20% disagreed, 10% strongly disagreed, and 0% did not know (Table 12).

<table>
<thead>
<tr>
<th>Scale</th>
<th>% use savings</th>
<th>% give up necessities</th>
<th>% no extras</th>
<th>% too expensive</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>35</td>
<td>40</td>
<td>50</td>
<td>60</td>
</tr>
<tr>
<td>2</td>
<td>15</td>
<td>25</td>
<td>25</td>
<td>10</td>
</tr>
<tr>
<td>3</td>
<td>30</td>
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<td>25</td>
<td>20</td>
</tr>
<tr>
<td>4</td>
<td>15</td>
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<td>10</td>
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<tr>
<td>5</td>
<td>5</td>
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<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
</tr>
</tbody>
</table>

Community Resources

Community resource items revealed the most utilized service was Meals on Wheels (13 couples). The service least used was adult day care. Homemaker services were used by 5 of 15 respondents. Day care services were utilized by 2 couples, respite care by 9, home health aides by 8, and transportation services were used by 4 (Table 13). The majority of responses indicated they needed respite care in some form.

<table>
<thead>
<tr>
<th>Score</th>
<th>Homemaker</th>
<th>Day Care</th>
<th>MOW</th>
<th>Respite</th>
<th>HHA</th>
<th>Trans</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>5</td>
<td>2</td>
<td>13</td>
<td>9</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td>No</td>
<td>15</td>
<td>18</td>
<td>7</td>
<td>11</td>
<td>12</td>
<td>16</td>
</tr>
<tr>
<td>Total</td>
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<td>N=20</td>
<td>N=20</td>
<td>N=20</td>
<td>N=20</td>
<td>N=20</td>
</tr>
</tbody>
</table>
ANALYSIS

Qualitative Analysis Results

Three questions requested open-ended comments. The first question asked: "Tell me your thoughts and feelings about placing your husband in a nursing home." Of the twenty responses, two answered "no" they would not consider out of home placement as an option and did not wish to discuss it. Six said that they would not consider placement of their husbands due to their commitment and values in caring for them. Three denied any problem existed which would require placement. Three stated it was too expensive and they could not afford placement. Two stated they would consider placement if their personal health deteriorated. Two felt they could not care for their husband and were considering placement. One felt no one would want him, but she needed to place him. And one did not trust the system and feared losing their home.

The second question asked: "What things do you need help with?" Six responded that they needed respite services. Three needed house keeping services. Two stated they needed someone to shop for them. Two answered they needed someone to do their laundry. Two replied that they needed everything, (additional help in the home). One
needed someone to run errands. One needed a home health aide to assist with bathing. One needed more money.
The majority of responses indicated they needed respite care in some form. This service is available through Regional Centers, but it is not reaching a large portion of this community. Many caregivers indicated they were unaware of this service, and were interested in applying. Many could not afford to hire help privately. In some situations, the caregivers were unable to leave their husbands in someone else’s care due to increased anxiety and separation issues of the patient.

The third question asked: “Who else helps you?” Nine responded that their children and/or grandchildren helped. Four answered they had no one to help out. Three had family members that help. Two had friends that help out. Two had In Home Supportive Service providers.

The results clearly indicated children and family members contributed help. This study did not indicate how much help was provided. These couples lived alone. In many cases family members were helping, but it was not adequate support. Formal services like In Home Supportive Services were underutilized. This may have been due to financial incomes exceeding the Medi-Cal guidelines to qualify for this program.
Bivariate Analysis

The Pearson correlation was used to analyze the relationship between the dependent variable, placement, and each of the independent variables. There were ten variables that demonstrated a significant relationship for out of home placement (Table 14). The range for p value was from 0.001 to 0.053, and the r value from 0.462 to -0.676.

Significant Correlation

The first variable significantly associated with placement was caregiver and patient age, indicating the older the couple, the higher the probability of placement (Table 14). This was true for both the caregiver’s age, and the patient’s age.

Statistical findings relative to Sociability measures (Table 14) indicated a significant correlation with placement on four items. They were; (1) if the AD patient scored low in the ability to be clean and neat, (2) If the patient physically struck out at people, (3) If the patient saw things that were not there, and (4) If the patient wandered inside the house.

Two items from the Impact on Relationship questions were significant. They were; (1) The wife had feelings of resentfulness, and (2) The wife felt as though she were being manipulated by her husband.
Impact on Social Support correlation's were significantly associated with placement on one item, the wife having less contact with family and friends.

One item from the Cost of Care Index correlated significantly with placement, the cost of care causing a dip into savings meant for other things.

<table>
<thead>
<tr>
<th>Variable</th>
<th>r</th>
<th>p</th>
<th>df</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver Age</td>
<td>-0.552</td>
<td>0.018</td>
<td>19</td>
</tr>
<tr>
<td>Patient Age</td>
<td>-0.526</td>
<td>0.017</td>
<td>19</td>
</tr>
<tr>
<td>Patient is Not Clean/Neat</td>
<td>-0.439</td>
<td>0.053</td>
<td>54</td>
</tr>
<tr>
<td>Patient Strikes Out</td>
<td>-0.457</td>
<td>0.043</td>
<td>38</td>
</tr>
<tr>
<td>Patient Sees/Hears Things</td>
<td>-0.459</td>
<td>0.042</td>
<td>38</td>
</tr>
<tr>
<td>Patient Wanders</td>
<td>-0.676</td>
<td>0.001</td>
<td>38</td>
</tr>
<tr>
<td>Wife Resentful</td>
<td>0.462</td>
<td>0.040</td>
<td>62</td>
</tr>
<tr>
<td>Wife Feels Manipulated</td>
<td>0.449</td>
<td>0.047</td>
<td>62</td>
</tr>
<tr>
<td>Decreased Social Contact</td>
<td>0.450</td>
<td>0.047</td>
<td>39</td>
</tr>
<tr>
<td>High Costs Reduce Savings</td>
<td>0.459</td>
<td>0.042</td>
<td>47</td>
</tr>
</tbody>
</table>

Regression Analysis

A regression analysis was applied so that the impact of multiple independent variables could be considered simultaneously. This type of analysis of variance controls for extraneous variables by treating them as covariant (Table 15).
Table 15. Regression Analysis - Adjusted Squared Multiple

<table>
<thead>
<tr>
<th>Variable</th>
<th>b</th>
<th>r²</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Wanders</td>
<td>0.039</td>
<td>0.104</td>
<td>0.809</td>
</tr>
<tr>
<td>Reduced Social Contact</td>
<td>-0.048</td>
<td>-0.107</td>
<td>0.685</td>
</tr>
<tr>
<td>Wife Resentful</td>
<td>-0.089</td>
<td>-0.218</td>
<td>0.663</td>
</tr>
<tr>
<td>Wife feels Manipulated</td>
<td>0.191</td>
<td>0.455</td>
<td>0.405</td>
</tr>
<tr>
<td>Wife's Age</td>
<td>0.027</td>
<td>0.580</td>
<td>0.280</td>
</tr>
<tr>
<td>Patient Sees/Hears things</td>
<td>-0.156</td>
<td>0.043</td>
<td>0.279</td>
</tr>
<tr>
<td>Patients Age</td>
<td>-0.025</td>
<td>-0.500</td>
<td>0.275</td>
</tr>
<tr>
<td>Patient Not Clean</td>
<td>-0.150</td>
<td>-0.386</td>
<td>0.178</td>
</tr>
<tr>
<td>High Costs Reduced Savings</td>
<td>0.169</td>
<td>0.466</td>
<td>0.103</td>
</tr>
<tr>
<td>Patient Strikes</td>
<td>-0.191</td>
<td>-0.502</td>
<td>0.103</td>
</tr>
</tbody>
</table>

*r*=beta, *r²*=std coefficient, *p*=probability of success

Table 16. Analysis of Variance

<table>
<thead>
<tr>
<th>Source</th>
<th>Sum-of-Squares</th>
<th>DF</th>
<th>Mean-square</th>
<th>F-Ratio</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regression</td>
<td>2.837</td>
<td>10</td>
<td>0.284</td>
<td>2.796</td>
<td>0.069</td>
</tr>
<tr>
<td>Residual</td>
<td>0.913</td>
<td>9</td>
<td>0.101</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Analysis of Variance

The regression equation approached statistical significance (F=2.796, P=0.069) with a sum of squares for the regression of 2.837 (df=10) and a residual sum of squares of 0.913 (df=9) (Table 16). None of the individual variables in the equation were significant, likely because a conservator 2-tailed test was used. The multiple R for the regression was 0.87, indicating that 75.6% of the variance in willingness to place the spouse was explained by the variables in the equation.
CONCLUSION

Caregiver burden is a multidimensional concept. The actual care their husbands require and the subjective perception of burden that these caregiving tasks create affect a variety of aspects of caregivers’ day to day lives. These aspects need to be redefined as a limited number of dimensions that the caregiver’s experience.

All of the variables found to be important were significantly correlated with willingness to place. Although the multivariate analysis did not produce statistically significant results, it did approach significance. The small sample size and the low level of measurement used for the dependent variable did limit the robustness of the data. Therefore, the preliminary findings reported here are worthy of further exploration with larger samples. It would be especially useful to examine the same issues with caregivers after placement of the spouse.

The analysis clearly showed that caregivers do report feelings of burden and that they stemmed from the impairment that caused changes in objective conditions within the family.

Care of a spouse with a progressive dementia is unique in the coping or adaptational demands placed on long-term marital partners. A caregiver wife must continually change
expectations of her impaired partner, herself, and the informal and formal helping networks. She may be forced to let go of premorbid expectations without letting go of the validity of the couple’s shared past or the validity of her husband’s current presence and his needs. Wives report that these intimations of a gradually more separate future are threatening, particularly as intimacy in conversation and the quality of the marital relationship changes. Even supportive adult children can’t substitute for what is lost in healthy, mutual dependence within an intimate marital dyad.

The wife must think, plan, organize, initiate, and anticipate for an impaired spouse. It is not surprising that the couple’s individual identities are easily merged, and the behavior or well being of one has a profound effect on the other. The wife who cares for her memory impaired husband must balance her longing for total fulfillment with new needs for separate boundaries or new definitions of herself as protective kin or surrogate decision maker.

Married partners may expect to care for each other in a final illness, but they rarely anticipate the need to separate psychologically or physically during the final illness. For caregivers, letting go begins when they must make decisions and judgments without guidance, input, or
support of the impaired husband. For many women, this begins when they are forced to ask for or use outside help, either from family or from formal sources.

This research examined the relative importance that one traditional measure of mental impairment, cognitive incapacity plays in understanding caregiver stress effects. Cognitive incapacity was compared with other symptoms of mental impairment, such as social functioning and disruptive behavior. The patient’s cognitive incapacity was less stressful for the caregiver than other symptoms. This may be due to cognitive symptoms being the first sign of mental deterioration. For patients whose cognitive capacity declines further, it may eventually produce symptoms such as disruptive behavior or impaired social functioning.

This research clearly indicated that caregivers’ assessments of the likelihood of institutionalizing Alzheimer’s’ husbands were influenced by several interrelated factors: characteristics of the caregivers, their relationships, and the impairment. Anticipated institutionalization was greater if the patients were older, their impairment had progressed rapidly and had rendered them more dysfunctional. The likelihood of institutionalization was also greater if the caregivers perceived more burden, and if their relationship with the
Another significant finding was the caregiver experiencing a conflict situation in at least two ways. First, was the love-hate dilemma. The caregivers reported feelings of frustration, sadness, and confusion while at the same time expressing love and compassion for their husband.

The second was the institutionalization paradox. The study suggested that the caregivers wanted to avoid premature or early institutionalization at almost any cost, but they indicated that there was probably some time when it will be inevitable. Several of them said that as long as they were healthy or that their husband was not dangerous, they would not place him in a nursing home.

The provision of care to the Alzheimer patients and their families has become a major service delivery and public policy issue in the United States and has important implications for the practice of social work. Recognition of the interdependence of family members (Brody, 1989; Hartman & Laird, 1983) is a fundamental theoretical perspective among social workers who often provide services to families caring for the Alzheimer's patient. In many cases, caregivers are the gatekeepers to the long term care system in this country, influencing the amount of public resources allocated to the care of the patients.
Profiles of components of burden permit further assessment of caregiving dynamics that have applied implications. Determining correlates of both the overall Cost of Care Index and the respective components serve to identify areas for professional counseling and intervention. The identification of caregivers who are experiencing burden, or potential caregivers who anticipate experiencing burden, can lead to professional assistance in relieving the causes of burden or planning for future assistance.

The delay of institutionalization may not always be the desired goal in future intervention studies and program development. It may be more desirable to consider improved quality of life, at home or institutions, as the more realistic and valuable outcome. The fact is that some patients need to be institutionalized and that others, such as individuals without primary caregivers, will always be at high risk for institutionalization. Wives who delay the decision for institutionalization, may need help in the decision making process. Other caregivers, who experience a high level of burden and have particularly negative reactions, may benefit from the early placement of their dependent and experience a significant decrease in burden and improvement in health after they are relieved of this role.
These findings suggest that we need to broaden the scope of research and interventions with families of Alzheimer’s disease patients to include all or most members of the family system. If the health related costs of the disease are to be considered, and if the processes of care are to be recognized more fully, then the broad context of caregiving needs to be a focus of systematic study.
APPENDIX A

QUESTIONNAIRE

ID # __________________________  Interview Date: ______

CAREGIVER INFORMATION

Age __________

Ethnicity: 
- Caucasian
- African American
- Mexican American
- American Indian
- Asian/Pacific Islander
- Other __________

Employment Status: 
- Full-time
- Part-time
- Not employed
- Retired

Annual Household Income: 
- Under $9,999
- $10,000 - $14,999
- $15,000 - $19,999
- $20,000 - above

Rate Current Personal Health: 
- Excellent
- Good
- Fair
- Poor

Level of Education: __________

Date of Marriage: __________

PATIENT INFORMATION

Ethnicity: 
- Caucasian
- African American
- Mexican American
- American Indian
- Asian/Pacific Islander
- Other __________

Age __________

I am going to read you a list of statements and you tell me for each one of them whether you:

Strongly Agree=1  Agree=2  Disagree=3  Strongly Disagree=4  Don't Know =5
SOCIABILITY

My husband is interesting to talk to. 1 2 3 4 5
My husband is enjoyable to be with.
My husband is friendly and sociable toward people.
My husband seems interested in things.
My husband is cooperative.
My husband is clean or neat about self.
My husband is appreciative or grateful for help.
My husband is withdrawn or unresponsive.

DISRUPTIVE BEHAVIOR

My husband complains or criticizes things.
My husband interferes with me.
My husband fails to respect privacy.
My husband yells or swears at people.
My husband does embarrassing things.
My husband disrupts meals or makes them unpleasant.
My husband physically strikes out at people.

COGNITIVE ABILITIES

My husband is confused.
My husband is forgetful.
My husband hears or sees things that are not there.
My husband wanders inside the house.
My husband has unrealistic fears.
My husband talks or mumbles to self.
My husband repeats self.
My husband does things harmful to self and others.

IMPACT ON RELATIONSHIP

I feel angry toward elder.
My relationship with my husband makes
me depressed.
My relationship with my husband is strained.
I feel resentful toward my husband.
I feel my husband tries to manipulate me.
I wish my husband and I had a better relationship.
My relationship with my husband gives me pleasure.
I feel my husband makes more requests than necessary.
I feel that my husband can only depend on me.

IMPACT ON SOCIAL SUPPORT

I take part in group/organized activity less.
I take part in theater, concerts, and shows less.
I visit family/friends less.
I take part in volunteer activities less.
I feel my social life has suffered because of my husband.
I don’t have enough time for self.
I take part in church related activities less.
I take part in other social activities less often.

COST OF CARE INDEX

I feel that caring for my husband is causing a (will cause) dip into savings meant for other things.
I feel that we must give up (or will give up) necessities because of the expense to care for my husband.
I feel that we can not (will not be able to) afford those little extras because of the expense to care for my husband.
I feel that caring for my husband is (will be) too expensive.
COMMUNITY RESOURCES

I have a homemaker service. □ □
My husband attends day care. □ □
We use Meals on Wheels. □ □
I get respite care. □ □
We have a Home Health Aide. □ □
We use special transportation. □ □

QUALITATIVE

Tell me your thoughts and feelings about placing your husband in a nursing home.

What things do you need help with?

Who else helps you?

52
March 14, 1997

Dear Caregiver,

I am writing to confirm our telephone conversation on March 14, 1998. I have requested your participation in a research project. This study will explore how decisions are made by wives of Alzheimer’s husbands to either obtain additional help in the home, or place the husband in a nursing home. This project will be conducted in conjunction with the Social Work Department at California State University, San Bernardino. Your participation in this study would be completely voluntary and would have no effect on the services you are currently receiving or may receive in the future. It is my hope that the results of this study will aide in future understanding and development of services for caregivers.

Participation in this project would involve one 60 minute interview. This interview will consist of questions regarding your experiences as a caregiver, difficulties you may be having, support and help you are receiving, and any help you still need.
I am confirming our appointment scheduled for February 20, 1998 at 3:00 p.m. Thank you. I look forward to our meeting.

If you have any questions or concerns, please contact Mary Klein, 760-241-8000.

Sincerely,

Rebecca Smith
Student Researcher
APPENDIX C

INFORMED CONSENT

TITLE OF STUDY: A Study of Factors in the Decision Making Process for Out of Home Placement by Wives whose Husbands have Alzheimer’s Disease.

PRINCIPAL INVESTIGATOR: Rebecca Smith

I UNDERSTAND THE FOLLOWING:

(1) Purpose of the study and how long it will last:
   I understand and consent that the Principal Investigator, Rebecca Smith, is participating in a research study being conducted by students in the Master’s of Social Work program at California State University - San Bernardino. This study is designed to analyze the decision making process of a married couple where the wife is the caregiver of her Alzheimer’s Diseased husband. Approximately 20 couples will participate in this one-time survey.

(2) Description of the procedures: I understand it will take approximately 60 minutes for the interview. I understand I will sign an Informed Consent form which will be provided by and returned to the researcher.

(3) Potential risks of the study: I understand that answering these questions may leave me thinking more about how much I have to do. A resource that could assist me in getting more services will be provided during the interview. No other known risks are known. I also understand that my participation in this project will have no effect on the services I am currently receiving or the service that I may receive in the future from Desert Valley Hospital.

(4) Potential benefits of the study: By providing Rebecca Smith assistance in this project, I will have the opportunity to participate in the study. There is no financial compensation for participating in this study.

(5) Withdrawal from the study: I understand that I do not have to take part in this study. My decision not to participate will involve neither penalty nor loss of benefits to which I might otherwise be entitled.

(6) Confidentiality/Use of the research results: The information obtained by patients seen in this project
will be kept strictly confidential. The results of this study may be published and shared with persons within the California State University - San Bernardino, Social Work Department, but will not identify any of the participants.

(7) Questions or concerns related to the study: If I have questions or concerns about the research or the rights of the related subjects, I may contact the Director of the Social Work Department, California State University San Bernardino, CA. 92407, 909-880-5501.

Participant's Signature

Date

Researcher's Signature

Date
APPENDIX D

DEBRIEFING STATEMENT

If any questions or concerns arise as a result of this project interview, the individuals named below may be contacted. Ms. Smith or Ms. Klein can also provide you with assistance in obtaining resources. You may also refer to the resource booklet left in your home the day of the interview.

In addition, the results of this study will be available at the California State University, San Bernardino by June 17, 1998.

Thank you very much for your participation in this research project.

Social Work Researcher:

Rebecca Smith
Student Researcher
760-241-8000 ask for Social Services

Desert Valley Hospital Representative:

Mary Klein, L.C.S.W.
Social Services Coordinator
Phone 760-214-8000

Master’s of Social Work Department, California State University, San Bernardino Contact Representative:

Dr. Rosemary McCaslin
Project Advisor
Phone 909-880-5501
REFERENCES


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U.S. Congress, Office of Technology Assessment, April 1987, Losing A Million Minds-Confronting the Tragedy of Alzheimer's Disease and Other Dementia's, Washington, DC

