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# Effects of alzheimer's day care

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EFFECTS OF ALZHEIMER'S DAY CARE

A Thesis

Presented to

The Faculty of the Department of Nursing

San Jose State University

In Partial Fulfillment

of the Requirements for the Degree

Master of Science

By

Rachel K. Holz

August, 1989

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## ABSTRACT

### EFFECTS OF ALZHEIMER'S DAY CARE

by Rachel K. Holz

A retrospective data analysis was used to investigate the difference in Activities of Daily Living scores of Alzheimer's clients following 6 months of Alzheimer's day care. The study also investigated the difference in primary caregivers' Burden scores following this day care. Lastly, it investigated the relationship between the client's Activities of Daily Living scores and Burden scores of caregivers. Data sets from 8 clients and their caregivers were analyzed.

The data indicated that functional abilities of Alzheimer's clients and caregiver burden levels did not change significantly. No statistically significant correlation was found between the clients' functional abilities and caregivers' burden levels. These data suggested that:

1. Alzheimer's day care may have had a positive effect on the clients, by maintaining functional abilities; and on caregivers, by preventing increased burden.
  2. The burden level of caregivers should not be predicted by clients' functional abilities.
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## Chapter 1

### INTRODUCTION

Alzheimer's disease has gained recognition as a major public health problem in this country. Today, Alzheimer's disease affects approximately 5% of the United States population 65 years of age and over and 22% of the population 80 years and older (Krale, 1986). It is presently the fourth leading cause of death in adults (Kahan, Kemp, Staples, & Brummel-Smith, 1985). This tragic disease produces an irreversible, progressive dementia, presently without cure. The course of the disease is one of unremitting mental and physical deterioration and often lasts for over 5-10 years (Mello, 1988). As the disease progresses, clients require 24-hour care and supervision sometimes described as the "36 hour day" (Mace & Rabins, 1981).

Over the long course of the disease, family caregivers provide the majority of care for the individual afflicted with Alzheimer's disease (United States Department of Health & Human Services, 1984). Studies of dependent, frail elderly show that family caregivers provide 80-90% of their care (Brody, 1985). According to data compiled by the California Alzheimer's Disease Task Force (Mello, 1988), more than 75% of all individuals with dementia live at home and are attended by family caregivers. Caring for an individual afflicted with Alzheimer's disease at home may

pose overwhelming physical, emotional, and financial stresses that may disrupt the caregivers' state of adaptation and jeopardize their mental and physical health.

Caregivers have begun to appeal for relief from the burden of caring for someone with Alzheimer's disease (United States Congress, Select Committee on Aging, May, 1985). Beginning 5-10 years ago, adult day care centers for individuals with Alzheimer's disease were developed in an effort to ease caregiver burden and decrease the stress of caregiving (Keyes & Szpak, 1983; Sands & Suzuki, 1983). A 1984 survey of adult day care for dementia clients in the United States (Mace & Rabins, 1984) estimated approximately 2,400 clients were served by these specialized centers, representing 5% of all adult day care clients.

In California the legislature passed a bill, SB 1337, in 1984, which authorized a 3-year pilot project for 8 Alzheimer's day care resource centers to be established and evaluated. In 1987, the centers were authorized for another 3 years. Presently in California, there are 18 such centers administered by the California Department of Aging. One of these centers was the setting for this study.

Alzheimer's day care centers are designed as an intervention to provide respite, referral, education, and support for caregivers. They provide recreation and social activity for clients with Alzheimer's disease, and disseminate information to the public regarding the disease.

It is hoped that the intervention of Alzheimer's day care will decrease the burden and stresses of caregiving, and promote adaptation to the Alzheimer's client's declining condition. But research is needed to determine specifically what effects Alzheimer's day care has upon the burden experienced by the caregivers as well as its effect on clients. This study attempts to address these questions.

#### Problem and Research Question/Hypothesis

The burden of caregiving for the individual with Alzheimer's disease is well documented (Cohen, Coppel, & Eisdorfer, 1982; Mace & Rabins, 1981; Zarit, Orr, & Zarit, 1985). While it has been established that the availability of a supportive family caregiver is a major factor in preventing institutionalization of individuals with dementia (Haley, Levine, Brown, Berry, & Hughes, 1987), who is supporting the caregivers? It is currently believed (Cohen, et al., 1982) that families are not receiving the support and training they need to effectively care for relatives with dementia. Caregivers endure a tremendous burden as they struggle to provide physical care, manage the difficult behaviors of the client, find their way through often uninformed agencies, and grieve as the client gradually declines. Health care needs of the individual with Alzheimer's disease may be addressed by family and professionals, but caregiver needs--social, emotional, and educational--are often not recognized (Scott, Roberto, &

Hutton, 1986). Caregiving for Alzheimer's clients has been shown to have adverse effects on the caregiver's physical and mental health, employment financial status, and social activity (Haley, et al., 1987; U.S. Department of Health & Human Services, Sept., 1984; Yankelovich, Skelly, & White, 1986).

Although there is a paucity of quantitative data, anecdotal data supports Alzheimer's day care as beneficial for clients and families (Yankelovich, et al., 1986). Alzheimer's day care provides caregiver respite, which caregivers consistently rate as their greatest need and greatest benefit from day care programs. It also provides caregivers with support and education to assist them to adapt to the decline of the client, and in making informed decisions regarding care and placement of the client. Such anecdotal data suggests that institutionalization is delayed in many cases where day care is available to the caregiver (Sands & Suzuki, 1983).

There is little empirical data available regarding effects of day care on the client with Alzheimer's disease. Day care programs vary in setting, staffing, and services; to some extent reflecting local needs and resources. The majority of programs strive to maintain the functional level of the client as long as possible. No program proposes to restore the lost functions of clients. Goals for clients at these centers include maintaining self-esteem, providing



meaningful relationships and activity, as well as providing structure, orientation, and constancy.

This study investigated the following three research questions. First, is there a difference in the level of burden experienced by Alzheimer's caregivers after 6 months of participation in Alzheimer's day care by the client with Alzheimer's disease? Second, is there a difference in the functional level of the client with Alzheimer's disease after 6 months of participation in Alzheimer's day care? Third, is there a relationship between the functional level of clients with Alzheimer's disease and the burden experienced by their caregivers during this 6 months of participation in an Alzheimer's day care program?

It was hypothesized that the burden level of Alzheimer's caregivers would not differ after 6 months of participation in Alzheimer's day care by the Alzheimer's victim. It was also hypothesized that the functional level of the client with Alzheimer's disease would not differ after 6 months of Alzheimer's day care. Finally, it was hypothesized that there would be no relationship between the burden level of caregivers and the functional level of Alzheimer's clients after the 6 months.

#### Purpose and Need

The basic purpose of the study was to investigate the effects of clients' participation in an Alzheimer's day care program and the burden experienced by their caregivers. In

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this study, burden was measured by Zarit's Burden Interview (Zarit, Orr, & Zarit, 1985, p. 84) which reflects the stresses experienced by caregivers of individuals with dementia. A second purpose was to investigate what effect this participation had upon the clients' functional level (ability to carry out normal activities of daily living). In this study, functional level related to scores on an Activities of Daily Living Assessment Tool. The final purpose was to investigate what effect the functional level of the client had on caregiver burden. This type of research data is needed to demonstrate some of the effects of Alzheimer's day care. It would be useful to day care administrators to gain support for their programs, and to help them prioritize and improve services to clients and families. It would be useful to policy makers and health care professionals in evaluating these programs and comparing various care settings for Alzheimer's clients. It would also be helpful to caregivers and clients who may use day care to understand its role and purpose. Lastly, this data could be useful to other researchers specifically in the areas of adult day care, caregiver burden, and comparing care settings.

Alzheimer's disease is markedly age dependent. Since the over 80 population is this country's fastest growing population, prevalence is expected to increase. Thus, it is vital for nurses to become educated and involved in

Alzheimer's disease management. Hayter (1982), a nurse involved in Alzheimer's issues states, "nurses can make a tremendous contribution to the well being of relatives by helping them cope with what is for most of them a very frightening, difficult experience" (p. 86). Nurses can supply information about the disease, offer coping strategies, suggest approaches to exhibited behaviors of the client, offer support and counseling, assess the level of functioning and care needs, assist in placement and in referrals. Alzheimer's day care provides a setting where nurses can provide and coordinate these interventions. Nurses in other settings also are affected by Alzheimer's day care programs--case managers, public and home health nurses, hospital discharge planners, primary care nurses in doctors' offices and in clinics. Thus, this study has particular significance to nursing.

#### Setting and Sample Population

This study was based on data collected by staff at an Alzheimer's day care center in Northern California in the years 1985 through 1988. The center began in 1985, as part of a 3-year pilot project of the State of California Department of Aging. It is also associated with the local adult school and the local Visiting Nurse Association. Alzheimer's clients attend a 5-hour-a-day, 3-day-a-week program of activities to provide mental and physical stimulation--such as socialization, walks, music, physical

therapy, personal care, arts, and crafts. Caregivers receive respite, information and referral, and attend family support groups. The staff of the center consists of a director (who is an occupational therapist), a recreational therapist, an occupational therapist, two instructional aides, and volunteers. A geriatric nurse practitioner works 3 hours a week performing health monitoring and coordinating care with clients' physicians. She monitors clients' medications and works with center staff, client, families, and physicians. The center has space for 18 moderately impaired participants with Alzheimer's disease or other types of dementia; 40% of whom are between the ages of 80 and 89.

This Alzheimer's day care center was chosen for the study as it was required by the State to systematically collect data on clients and caregivers. Frequently day care centers do not have staff available to collect such data, nor requirements to do so. The availability of this data made this study possible.

The sample was taken from recorded written interviews with primary caregivers of Alzheimer's clients attending the center. Interviews were conducted by the director of the center, the recreational therapist, and the occupational therapist.

The following criteria were used to include data in the study. First, the person interviewed had to be the primary caregiver. The client had to have attended the day care program for 6 consecutive months. Clients had to have a documented diagnosis of Alzheimer's disease from their physician. Lastly, the interviews had to be completed at 6-month intervals, on admission and 6 months following. Since 1985, 35 clients had attended the day care center program and their interviews were available for the study. Only 8 of these met the study criteria and were used. No human subjects were used in this study (Appendix A).

#### Definition of Terms

For the purpose of the study, the following terms are defined:

1. Primary caregiver: Layperson principally responsible for providing or coordinating resources required by the person with Alzheimer's disease.
2. Burden: A summary outcome measure representing physical, psychological, financial, and emotional stressors.
3. Alzheimer's day care: Adult day care designed specifically for persons diagnosed with Alzheimer's disease, and providing education, support, and referral for the caregiver.
4. Functional level: A summary outcome measure based on an evaluation of activities of daily living and

instrumental activities of daily living representing self-care ability.

#### Research Design and Methodology

A retrospective secondary data analysis was used for this descriptive study. The following data, collected by the staff of an Alzheimer's day care center, was analyzed using descriptive statistics and basic inferential statistics:

1. The Zarit Burden Interview (Zarit, et al., 1985, p. 84) was administered to the primary caregiver upon admission of the client to the center, and after 6 months of participation in the center's program (see Appendix B). The Burden Interview was designed to reflect the stresses experienced by caregivers of dementia clients.

2. The Activities of Daily Living/Instrumental Activities of Daily Living Tool, an assessment tool used by this day care center, was also administered to primary caregivers along with the Burden Interviews at 6-month intervals described above (see Appendix C). Hereafter, this assessment tool will be referred to as the A.D.C. ADL/IADL Tool.

The data from the two Burden Interviews administered at 6-month intervals were compared using the t-test to address the first research question--Is there a difference in the level of burden experienced by caregivers after 6 months of participation in Alzheimer's day care by the Alzheimer's

client? The data from the two A.D.C. ADL/IADL Tools administered at 6-month intervals were compared using t-tests to address the second research question--Is there a difference in the functional level of the client with Alzheimer's disease after 6 months of participation in day care? The third research question--Is there a relationship between the functional level of clients with Alzheimer's disease and the level of burden experienced by their caregiver over the 6 month period?--was analyzed using the Pearson Product Moment Correlation Coefficient.

#### Scope and Limitations

This study explored relationships between Alzheimer's day care, caregiver burden, and the functional level of the client. It was hoped that the results would provide preliminary data demonstrating the usefulness of this type of intervention in reducing the stressors and burden experienced by caregivers.

Major limitations of this study included lack of control over the methodology used in the original data collection process. Another limitation was the small sample size. A third limitation, related to the small population available, was the time interval of the study. Six months of data collection and analysis did not permit a thorough evaluation of long-term trends in client and caregiver outcomes when dealing with Alzheimer's disease. But, given the circumstances of a limited sample population, the rapid

downhill trajectory of the disease, and limited time for this research study, 6 months was chosen as reasonable to provide preliminary data.

Since this was a study that relied upon previously collected data, the researcher was not able to measure other variables such as caregiver depression. Caregiver depression is a key factor that other studies have found related to caregiver's level of burden. This was not measured as the original data collection process did not include it. Zarit et al. (1985, p. 84) suggests measures of depression be used along with the Zarit Burden Interview to supplement the findings. Another factor not measured was the amount of other available supports to individual caregivers.



## Chapter 2

### CONCEPTUAL FRAMEWORK AND REVIEW OF LITERATURE

The conceptual framework for this study is derived from Neuman's (1982) health care systems model of nursing. This holistic model revolves around stress and man's reaction to it. Neuman proposes three "levels of prevention" (p. 13) whereby nurses can affect the individual's reaction to stress. This theorist sees the goal of nursing as helping the client attain a maximum level of wellness and client system stability. The model reflects nursing's present interest in the total person and in concepts of wellness and prevention. The model can be easily applied to the subject of caregiver stress and burden, functional level of the Alzheimer's disease client, and the intervention of adult day care.

#### The Individual

Neuman (1982) views man as a "dynamic composite of the four variables--physiologic, psychologic, sociocultural, developmental" (p. 12). In the model, man is represented by a series of concentric circles. Neuman names a central core "Basic Structure Energy Resources" (p. 13). The core represents survival factors unique to each individual, but within a common range in all individuals. Surrounding this are circles representing varying lines of defense and resistance, which protect the core and maintain the individual's state of adaptation.

Caregivers as a group can be put in place of the individual in the model. Caregivers arrive at the new task of providing care to the client as a unique composite of sociocultural, psychological, developmental, and physiologic variables. Each caregiver differs, yet faces similar tasks. Some are older, some younger, some work, some do not, some are healthy, some have health problems, some deal with stresses well, some do not. As Alzheimer's disease is a democratic illness, it affects all races and socioeconomic groups. Thus, a true variety of caregivers is represented.

#### Stressors

Mariner (1986, p. 315) points out that Neuman uses Selye's definition of stress. According to Selye, stressors can be noxious or beneficial, and include the subconcepts of intra, extra, and interpersonal types of stressors. They can interact at any point with the individual from the core to the outermost line of defense. The interrelationship between stressors and the individual is variable and dynamic.

Stressors related to caregiving for this group are many. To illustrate a few--intrapersonal stressors include the loss of functional abilities of the client with Alzheimer's disease, which places physical and psychological demands on the caregiver. Development or worsening of caregiver health problems may occur. Grieving occurs as the client declines. Stress symptoms are three times more

prevalent in caregivers of Alzheimer's clients than non-caregivers (Yankelovich, et al., 1986). Interpersonal stressors include role changes--often the wife must become head of the household if her husband is a client, or the oldest daughter may assume this role. Social isolation is another stressor, as is lack of family support. External stressors include financial loss, employment loss, lack of facilities and services to assist the caregiver in their role, and changes in living arrangements (United States Congress, Office of Technology Assessment, 1985). The level of burden as measured by the Zarit Burden Interview (Zarit, et al., 1985, p. 84) reflects these stresses experienced by caregivers of dementia clients. The interview includes questions on financial stressors, physical stressors, psychological stressors, stress related health problems, and role changes.

#### Levels of Prevention

Neuman's model (1982) has three levels of prevention--primary, secondary, and tertiary. Primary prevention involves assessing and avoiding risk factors. This prevents stressors from breaking through the individual's "normal line of defense" (p. 13). Secondary prevention reduces the degree of reaction to stress and is based on symptomatology. The goal is to protect the basic structure core. Tertiary prevention assists in "reconstitution" (Neuman, 1982, p. 14)

which maintains adaptation and a strong line of defense against stressors.

Alzheimer's day care fits into Neuman's levels of prevention as follows. When describing Alzheimer's day care and its place conceptually in Neuman's model, effects upon both caregiver and Alzheimer's client must be considered. Day care provides respite, education, support, counseling, and referral for caregivers. For clients, day care provides assessment, structured activity, and socialization.

For the client, Alzheimer's day care functions mainly at Neuman's secondary level of prevention. The secondary level of prevention Neuman describes as treatment following occurrence of symptoms. Clients would not attend Alzheimer's day care prior to the development of the disease or its symptoms. As the etiology of Alzheimer's disease remains unknown, preventative activities are inappropriate and day care cannot be considered a primary level of prevention. At the secondary level of prevention, day care provides the client with symptom management. This includes management of behavior, memory loss, and loss of functional abilities. Neuman (1982) describes the secondary level of prevention as using all the individual's resources internally and externally to strengthen lines of resistance and defense. The following examples further illustrate day care's role in secondary prevention. Internally, day care works toward maintaining the client's general health.

Externally, day care works through structuring the environment for safety, decreasing stimuli and frustration for ease of functioning, day care strengthens lines of resistance and defense. Staff at the day care work with the caregiver to best utilize external resources.

For the caregiver, Alzheimer's day care ideally would be most helpful at the primary level of prevention--prior to the development of symptomatology in the caregiver. In reality, caregivers often wait to seek help until after their lines of defense and resistance are wearing down. Alzheimer's day care serves caregivers with or without symptoms, and often it isn't clearly primary or secondary prevention, but in between or overlapping. Thus a caregiver may come to day care prior to the development of symptoms (primary prevention), or after the development of symptoms (secondary prevention), and later may "reconstitute" (Neuman, 1982, p. 16)--adapt to the stressors (tertiary prevention).

Alzheimer's day care reduces the caregiver's reaction to stressors of this role, and strengthens their resistance to prevent stressors from causing symptoms. Caregiver symptoms might include illness or worsening of existing health problems, stress symptoms such as headaches, or increased use of drugs such as tranquilizers and sleeping medication. Other symptoms could be depression, or physical injury. As the majority of caregivers are spouses, often

elderly themselves, they may have pre-existing health problems that make them especially vulnerable to the added stresses of the caregiver role. While day care staff do not necessarily "treat" these symptoms, they provide referrals as needed and are trained to recognize signs and symptoms that may occur in the Alzheimer's caregiver.

At the tertiary level of prevention, day care can help to maintain over time a state of adaptation to the decline in the client's condition. By continuing services to caregivers, day care staff can help caregivers cope with the need to finally institutionalize the client if needed, and adapt to this. Thus, day care is an intervention that provides services at all three levels of prevention. The goals of nursing that Neuman identifies of helping the client (in this case, the caregiver and the Alzheimer's client) to attain maximum wellness and stability in the face of many types of stressors seems very realistic and relevant to this study.

#### Review of Literature

The review of the related literature is organized into four sections. Section one describes Alzheimer's disease caregivers. The second section discusses caregiver burden. The third section describes related literature on Alzheimer's day care and its effect on caregiver burden. The fourth section focuses on Alzheimer's day care and its effect on the client's functional level.

### Alzheimer's Disease Caregivers

As described previously, for purposes of this study, Alzheimer's disease caregivers as a group represent the "individual" in Neuman's model. The following is a more specific description of this group. A 1982 Long Term Care Study (Stone, Caffarata, & Sangl, 1986) found the average age of caregivers of frail or disabled elderly to be 57 years. Twenty-five percent were age 65-74 and 10% were over 75 years old. This was a comprehensive well done nationwide survey conducted by the federal government. According to a comprehensive study by Coons, Chenoweth and Hollenshead (1983), when an Alzheimer's client was married, the caregiver was most often the spouse. One-third to one-half of all caregivers were spouses. If there was no spouse, the daughter or daughter-in-law assumed this role. One-fourth to one-third of Alzheimer's caregivers were adult children. There tended to be more women caregivers than men as women tend to outlive men.

### Caregiver Burden

As discussed previously, for purposes of this study, burden reflects the stresses imposed on the caregiver by the demands of caregiving. In Neuman's model these inter, intra, extra personal stressors affect the individual's level of wellness, and state of adaptation. The stresses of caregiving that were described in the literature affected

Alzheimer's disease caregivers' state of wellness, adaptation, and level of burden.

A major portion of the literature reviewed mentioned the prolonged, enormous demands of caring for an Alzheimer's client. The burden of caring for the client with dementia, some authors believe (Brody, 1981; Poulshock, 1982), was quite different from other chronic impairments. This caregiving was made more difficult by the unique characteristics of dementia such as personality changes that affect caregiver and client relationship, communication difficulties, lack of cooperation, lack of appreciation, bizarre and disruptive behavior, and the need for constant supervision (Mace & Rabins, 1981, p. 9).

The stress of caregiving for an Alzheimer's client could affect the caregiver in many ways. First, it could affect their health. In a nationwide long-term care study done in 1982 (Stone, Caffarata, & Sangl, 1986), one-third of caregivers of frail or disabled elderly rated their health as fair or poor. A study by Yankelovich, Skelly, and White (1986) of 2,900 persons found 12% of caregivers living with persons with dementia physically ill or injured as a result of caring for the person. As many caregivers were older themselves, they often had chronic illnesses associated with advanced age (Brody, 1985). The U.S. Congress Office of Technology Assessment (1987) report on Alzheimer's disease cited over 60 studies (p. 139) reporting high levels of



depression among caregivers. People caring for someone with dementia had three times as many stress symptoms as people of the same age who were not caregivers (Office of Technology Assistance, 1987, p. 139). Caring for a person with dementia often had adverse effects on the following: caregiver's participation in recreational and social activities (Rabins, Mace, & Lucas, 1983), employment (Brody, 1985), and financial security (United States Congress, Office of Technology Assessment, June, 1985).

Research on caregiver burden is in its early stages. Assessment instruments vary. Some focus on caregivers' subjective or emotional reaction--such as Zarit's Burden Interview. Others focus on objective indices such as increased use of alcohol and drugs by caregivers.

One of the first studies on caregiver burden was by Zarit, Reever, and Bach-Peterson (1980). This scientific study measured seven variables related to burden, studying 29 Alzheimer's clients and their caregivers. It found social support received by caregivers of Alzheimer's disease clients was associated with extent of burden--the more social support, the less the burden. Supporting these findings was a study by Scott, Roberto, and Hutton (1986) on caregiver burden, that again found increased social support, especially family support was associated with decreased caregiver burden levels. Zarit et al. (1985) later found that burden was not associated with the level of impairment,

suggesting that service providers should not assume how much stress the family is under just because of the diagnosis and clinical course. In this study of determinants of burden, Zarit (1985) described three predictors of burden in caregiving--amount of social support available, past relationships between caregiver and client, and coping mechanisms of the caregiver. Colerick and George (1986) found the caregiver support system a better predictor of institutionalization than characteristics and symptoms of the client--supporting Zarit's 1985 study. Theirs was a comprehensive well designed study of 209 caregivers of Alzheimer's clients with generalizable findings. The burden the caregiver experienced could be influenced by whether the caregiver and client shared a residence (Brody, 1985). Poulshock (1982) found caregiver stress increased in relation to the number of disruptive behaviors, and the extent of need for personal care.

#### Alzheimer's Day Care and Caregiver Burden

Day care for Alzheimer's clients is a recent intervention designed in part to decrease the burden and stress of caring experienced by caregivers of Alzheimer's clients. Since specialized day care for people with Alzheimer's disease is so new, minimal research has been done regarding its effects upon either caregivers or those afflicted. Studies are primarily descriptive.

A comprehensive descriptive study by Yankelovich et al. (1986) examined the services adult day care programs serving Alzheimer's disease clients are providing to caregivers. The study found over a period of 2 years that an adult day care program would typically provide the following services to caregivers: referral to a support group, referral to a dentist who takes clients with dementia, advice on behavior management, assistance in coordinating care with other family members, referral to a lawyer, referral to a home health aide, short-term counseling, help selecting a nursing home.

Sands and Suzuki (1983) reported on an Alzheimer's day care program after 2 years of operation. They claimed families consistently reported gaining relief and support. Within this program, family support groups were a means of promoting, sharing, and providing emotional support. Families frequently claimed that the client showed improvement in emotional behavior. Keyes and Szpak (1983) described an Alzheimer's day treatment program with 9 to 12 clients that had been in operation for a year. They stated that program evaluations and informal family responses demonstrated decreased caregiver burden. Burden level was not measured with a standardized instrument, thus their findings were limited. Panella, Lilliston, Brush, and McDowell (1984) presented a 4-year analysis of a day care program for dementia clients. This program had served 69

clients and their caregivers. This program analysis was more thorough and scientific than those previously cited. The caregivers in this study identified respite time as the greatest benefit. These caregivers felt the knowledge they obtained from center staff and support groups allowed them to care for the client at home longer. Twenty-four percent of the caregivers stated they would have had to consider placement in an extended care facility if the day care had not been available.

According to the administrator (personal communication, March, 1987) of the Alzheimer's day care center used in this study, 25% of the caregivers served stated they would have had to institutionalize the client if day care had not been available. Anecdotal data from the State of California Alzheimer's Day Care Resource Center Program Report of 1987 (Lindeman, Bogaert-Tullis, Teetz, Fox, & Benjamin, 1987) suggested that families who used one of the 8 Alzheimer's disease centers in California were able to keep the Alzheimer's client at home because respite was made available to them.

As these day care centers provide education and support groups for the caregiver, it is important to note some of the studies dealing with the effects of education and support groups upon caregiver burden. Zarit et al. (1985) found educational programs about the disease and support groups were valuable in relieving caregiver stress. Data

from Steuer (1984) also suggested support groups were effective in decreasing caregiver burden and stress.

#### Alzheimer's Day Care and Its Effect on the Victim

Day care is consistently reported to be beneficial to clients as well as providing respite to caregivers. In a 1984 national survey of 340 day care centers serving Alzheimer's disease clients, Mace & Rabins reported that the majority of centers found that clients made friends, had fewer emotional outbursts, and pacing and wandering behavior had decreased.

This investigator was unable to locate specific studies on Alzheimer's day care and self care abilities. Measures of activities of daily living were mainly used to assess what level of care was required rather than to monitor response to the care. A wide variety of tools measuring self care ability were found. The most widely used measure of activities of daily living was the Katz Index of Activities of Daily Living (Office of Technical Assistance, 1987, p. 272). Originally developed for patients with hip fractures, Katz's tool has been used in a variety of gerontologic and other healthcare settings. The Activities of Daily Living/Instrumental Activities of Daily Living tool used in this study was based on Katz's tool (Katz, Ford, & Moskowitz, 1963). It was developed by staff from the

California State Department of Aging not the day care center staff in which this study was conducted.

Katz (1983) reviewed over 25 research studies involving Activities of Daily Living/Instrumental Activities of Daily Living tools to examine reliability and validity of these tools. He found that for clinical evaluations, program evaluations, identifying and monitoring health problems requiring care in the elderly, these tools provided reliable and valid measures. While it is generally assumed that these tools measure self care ability, few studies address their use with dementia clients specifically. There are a few tools developed specifically for clients with dementia. One is the Dementia Scale (Blessed, Tomlinson, & Roth, 1968), and another is the Functional Activities Questionnaire (Pfeffer, Kurosaki, & Harrah, 1982).

The question of bias was addressed by Rubinstein, Schairer, and Wieland in 1984. They found the reliability of ADL/IADL tools was affected by rater bias. They compared ratings by patients, their nurses, and a family member or friend on three ADL/IADL scales. They found family members or friends rated the clients lowest, followed by the nurses, and that clients rated themselves the highest in ability.

Another factor affecting these tools was that the instrumental activities may not apply equally to male and female roles. A male may not have ever done laundry and cooking for example.

Summary of the Literature Review  
and Conceptual Framework

"Caregivers provide the motivational, emotional, and physical environment in which the Alzheimer's client must operate" (Cohen, 1982, p. 445). It is important for caregivers to maintain a state of wellness and adaptation as they shoulder the burden of care for the client. The literature review revealed many stressors associated with being a caregiver for an Alzheimer's client, including extra, intra, and interpersonal stressors. These stressors could break through caregiver lines of defense and resistance to affect caregiver health and well being. The subjective impact of these stressors on the caregiver, made up the caregiver burden level. As burden increases, the caregiver's lines of resistance and defense can be broken, and the caregiver may develop stress related symptoms such as new or aggravated health problems. Research studies have associated various factors with decreasing caregiver burden such as social supports, day care, respite, and education.

Data collected on Alzheimer's day care as an intervention at the primary, secondary, and tertiary level of prevention to decrease caregiver burden was limited. Available data suggest that it is beneficial, may decrease the reaction to stressors the caregiver experiences, and may allow caregivers to keep the client at home longer. Data on the effects of day care at the secondary level of prevention

upon the client were very limited. More research is needed to identify the interventions that may reduce caregiver stress and burden, with development and validation of improved procedures for measuring caregiver burden. Research is also needed to develop tools to specifically measure functional abilities of Alzheimer's clients.



## Chapter 3

### METHODOLOGY

This chapter details the methodology used for data collection in this study. The chapter will be organized into the following sections. First, the research design will be identified. Next, the instruments used for data collection will be described. Following this is a section outlining the sample and setting for the study. Finally, the specific procedures followed to collect the data will be discussed.

#### Research Design

The goal of the study was to explore the relationships between day care for the Alzheimer's client, level of functioning of the client, and caregiver burden. A retrospective secondary data analysis was done. Data was collected by staff at an Alzheimer's day care resource center in Northern California from 1985 to 1987. These data were analyzed using descriptive statistics and basic inferential statistics.

#### Data Collection Instruments

Data collection instruments consisted of Zarit's (Zarit, et al., 1985, p. 84) Burden Interviews (see Appendix B), and the A.D.C. ADL/IADL Assessment Tool (see Appendix C). These were administered to primary caregivers of clients of Alzheimer's disease before and after 6 months of participation by the client in the day care program.

### The Burden Interview

This interview was developed originally by Zarit, Reeve, Bach-Peterson in 1980, then revised by Zarit in 1982. The revised scale was used in this study. It provided five intervals of response from "never" to "nearly always" (Zarit, et al., 1985, p. 84) for 22 questions designed to evaluate the subjective impact of caregiving. Higher scores indicate greater caregiver distress. Results were rated on a 4-point scale--little to no burden, mild to moderate, moderate to severe, and severe.

Preliminary findings of its use in research suggests the revised scale taps dimensions of caregiver stress. Zarit (Zarit, et al., 1985) quotes Hassinger (1985) and Gallagher, Rappaport, Benedict, Lovett, and Silven (1985) as estimating internal reliability for the Burden Interview at .88 and .91 (using Chronbach's alpha). He quotes Gallagher, Rappaport, Benedict, Lovett, and Silven (1985) as finding test-retest reliability at .71. He states validity has been estimated by correlating the total score with a single global rating of burden ( $r=.71$ ) and correlating the total score with the Brief Symptom Inventory of Derogatis, Lipman, Covi, Richels, and Uhlenhuth (1970) ( $r=.41$ ).

Many problems affect reliability and validity of measures of caregiver burden. For example, depression could predate a caregiver's responsibilities (Poulshock, 1984). Family problems could be blamed on caregiving when not

related. The interview is based on the caregiver's subjective experience; thus accuracy is limited by the caregiver's ability to report feelings and problems as they exist. Another problem relates to control groups--without them it is hard to determine which caregiver's problems are related to caregiving and which to other variables. As most of the questions in the interview relate to caregiving, it would require modification prior to administration to a control group of non-caregivers.

The Alzheimer's Day Care Center Activities of Daily Living/Instrumental Activities of Daily Living Assessment Tool (ADL/IADL)

The ADL/IADL Tool used by the Alzheimer's day care center in this study included an Activities of Daily Living section. It listed nine personal care activities (grooming, dressing, bathing, eating/feeding, transfer, mobility/walking outside, mobility/walking inside, toileting, and continence care) which were rated by choosing one of six descriptions of how the client carried out the activity. These options ranged from complete independence to inability or refusal to perform the activity. In addition, eight instrumental activities were measured with similar options and scoring. Instrumental activities measured activities such as use of the telephone, handling finances, shopping, meal preparation, housework, medications, transportation, laundry, which affect independent functioning. Higher

scores indicated more impairment and lower scores less impairment. It is very important to stress that this score was not meant to be interpreted as a comprehensive measure representing a stage of the client's disease, or severity of the disease itself. It only related to self care functioning, not to cognitive functioning. Functional level is a term to be used strictly as defined in this study.

There are certain questions associated with using activities of daily living/instrumental activities of daily living tools with dementia clients. There is an absence of formal research on the reliability and validity of these instruments when used with dementia clients such as those with Alzheimer's disease. Clients with Alzheimer's disease often fluctuate in their abilities to perform tasks. They may become increasingly confused as the day wears on. They may be increasingly confused in an unfamiliar setting. They may simply choose not to cooperate and perform tasks of which they are capable. They may be able to physically carry out an activity, but lack the judgment of when and where to perform this activity--thus carrying it out might be unsafe or inappropriate. While there are special activities of daily living/instrumental activities of daily living instruments designed for dementia clients, they were not used by the Alzheimer's Disease center staff in the primary data collection process.

## Sample and Setting

### Sample

The convenience sample for this study was obtained from 36 primary data sets collected from primary caregivers of Alzheimer's clients by the staff of an Alzheimer's day care center in Northern California. The number of respondents who met study criteria was even smaller. Data to be analyzed had to meet the following criteria for inclusion in this study:

1. The person interviewed was the primary caregiver, and remained so for over 6 months.
2. The client had a documented medical diagnosis of Alzheimer's disease.
3. The client regularly attended the 3-day-a-week, 5-hours-a-day day care program for over 6 months following administration of the initial interview.
4. Interviews were given at 6 month intervals or within the range of 2 to 3 weeks of this time.

Specifically, 36 records were made available to this researcher. Eight data sets met the study criteria and were used. Of the data sets excluded, 5 respondents did not have a medical diagnosis of Alzheimer's disease. One respondent lacked the caregiver Burden Interview on admission. One respondent had other data missing. Six respondents had no second interview record. Four respondents died before completing 6 months of participation. Eight respondents

were discharged before 6 months of participation. Three respondents were not used because the dates between interviews were longer or shorter than the study criteria.

An analysis of the Alzheimer's day care center records was performed. A numerical coding system was already in place for each client. Thus, no names were used in the analysis. Approval to review the center records was obtained from the administrator of the center (see Appendix D). In the initial data collection process, clients and caregivers were informed of the data collection procedures prior to enrollment by the center administrator. Caregivers signed an agreement for the client giving permission for admission to the center.

The setting, an Alzheimer's day care center in Northern California, began operating in 1985. The stated purpose of this program was to help clients function at optimal level, to provide family members with respite, support, and information and to assure centralized access within the community to Alzheimer's related services and information. Services such as support groups, occupational and physical therapy, nutritional and health monitoring, activities and exercise, screening, referral, family needs assessment, and a resource library were provided to participants in a 5-hours-a-day, 3-days-a-week program. Thus, client and caregivers received services.

### Procedure

The procedures used by staff in the interview and data collection process were as follows: Upon admission of the Alzheimer's client to the day care program, a Burden Interview, an Activities of Daily Living/ Instrumental Activities of Daily Living Assessment were administered to their primary caregiver. The staff also did a general assessment of the client which included a Folstein, Folstein, and McHughes (1975) Mini Mental State Examination (MMSE), a brief health assessment completed by the client's doctor, and performed a Level of Severity Rating Index (LSRI). Only the Burden Interview and Activities of Daily Living Assessment were used in this present study. Every 6 months thereafter for as long as the client was enrolled, the primary caregiver and client were given these same tests. These were collected as part of a pilot project of the State of California. Data were collected and sent to the State Department of Aging. These data, collected from all the pilot Alzheimer's day care centers in California, have been compiled into a report (Lindeman, Bogaert-Tullis, Teetz, Fox, & Benjamin, 1987). This report describes each center and compares services and structure of the centers. Data on burden and functional level have not been analyzed. The ADL/IADL scores, Burden scores, and general assessment results were also used informally by center staff to determine level of severity of client's caregiver burden,

and to individualize a program to meet the needs of clients and caregivers.

The initial interview was conducted by the administrator of the program. Six-month follow up interviews were administered by the administrator or by one of the two staff members trained in interviewing by the administrator. One was an occupational therapist and the other was a recreational therapist. Procedures used in administering the interviews were consistent. Interviews were given in the center itself, in a secluded area, on an individual basis. No additional comments were elicited or collected as part of the interview.

The records at the day care, collected as described previously, were reviewed by the researcher. They were evaluated against study criteria as described. Results of the review produced 8 data sets for the study.



## Chapter 4

### ANALYSIS AND INTERPRETATION OF DATA

Three research questions were posed in this study. First, Is there a difference in the level of burden experienced by Alzheimer's caregivers after 6 months of participation in Alzheimer's day care by the client with Alzheimer's disease? To answer this, data from the two Zarit Burden Interview (Zarit, et al., 1985) administered at 6 month intervals were compared using the  $t$ -test. The raw scores and  $t$ -test results were analyzed and interpreted.

The second question asked, Is there a difference in the functional level of the client with Alzheimer's disease after 6 months of participation in Alzheimer's day care? To answer this question, data from the two Alzheimer's Day Care ADL/IADL Tools were compared using the  $t$ -test. The raw scores and  $t$ -test results were analyzed.

The third question asked, Is there a relationship between the functional level of the Alzheimer's client and the burden experienced by their caregivers during this 6 months of participation in an Alzheimer's day care program? To answer this, the change in Activities of Daily Living scores and the change in Burden scores were correlated using the Pearson Product Moment Correlation Coefficient. Raw scores and correlation results were analyzed and interpreted.

It was hypothesized that the burden level of Alzheimer's caregivers would not differ after the intervention of day care, nor would the functional level of the clients. It was further hypothesized that there would be no relationship between the burden level of caregivers and the functional level of clients.

The researcher also included an analysis and interpretation of individual item results on the Burden Interview and A.D.C. ADL/IADL Tool. This consisted of a ranking of mean scores to each individual question. This data was presented to identify trends that may have clinical significance.

Research Question #1: Alzheimer's Day Care and Level of Burden

Data utilized to answer this question were Burden Interviews on admission (Burden 1) and 6 months following (Burden 2) participation in Alzheimer's day care to caregivers. These scores were compared and analyzed with the t-test. The raw scores indicated that 3 of the 8 caregivers (38%) had an increase in burden over the 6 month period. Two of these caregivers had an increase from the mild-moderate level to the moderate-severe level. One increased from the little-none level to the mild-moderate level. Five of the caregivers (62%) experienced no change in their burden level. The mean score, shown in Table 1, of the first Burden Interview was 33.8, (SD-17.34) a score

representing mild to moderate burden. The mean score of the second interview was 37.25, (SD-15.74) still within the mild to moderate burden level. The mean change was 3.875 (SD 9.92), which was not statistically significant ( $t(7) = 1.10$ ,  $p = .15$ ). In summary, the data demonstrated that while the client participated in the day care program, caregiver burden stayed relatively stable. The data supported the hypothesis that after 6 months of Alzheimer's day care, there would be no difference in caregiver burden.

Table 1

t-Test for Difference in Burden Interview Scores of Alzheimer's Disease Caregivers Following 6 Months of Alzheimer's Day Care. (N = 8)

	<u>M</u>	<u>SD</u>	<u>t</u>
Burden 1	33.8	17.34	1.10
Burden 2	37.25	15.71	
Change in Burden Mean	3.88	9.92	

$p < .05$

Research Question #2: Alzheimer's Day Care and Functional Level

Data utilized to answer this question were initial Activity of Daily Living scores (ADL 1) and scores 6 months later (ADL 2). These scores were compared, then analyzed using the  $t$ -test. Note that the A.D.C. Tool gives an ADL

score as well as an IADL score. While both scores were .pa examined for trends, only the ADL score was used for the  $t$ -test.

The raw scores indicate that 2 of the 8 clients (25%) had ADC ADL/IADL scores that decreased. This represents that in these 2 cases, caregivers found the client to have improved as far as their functional self-care abilities were concerned. Four scores (50%) increased, representing that in 4 cases caregivers found the client to have decreased functional levels. Two scores (25%) were unchanged over the 6 month period, representing no change in functional level. Table 2 presents the mean, mean change, standard deviation, and  $t$ -test results. The first ADL mean score was 14.87 ( $SD=7.12$ ). The second ADL mean score was 18.13 ( $SD=7.45$ ). The mean change between these scores was 3.25 points ( $SD=6.51$ ). This change was not statistically significant according to the  $t$ -test results ( $t(7) = 1.41, p = .10$ ). The data supported the hypothesis that after the client participated for 6 months in an Alzheimer's day care program, no difference in functional level was found.

### Research Question #3: Functional Level and Burden

To analyze this question, the change in Burden scores over the 6 month period and the change in Activity of Daily Living scores over the 6 month period were correlated using the Pearson's Product Moment Correlation Coefficient. In Figure 1, change in A represents the change in the

Table 2

t-Test for Difference in Activity of Daily Living Scores of Alzheimer's Clients Following 6 Months of Alzheimer's Day Care. (N = 8)

	<u>M</u>	<u>SD</u>	<u>t</u>
ADL 1	14.87	7.12	1.41
ADL 2	18.13	7.45	
Change in ADL	3.25	6.52	

$p < .05$

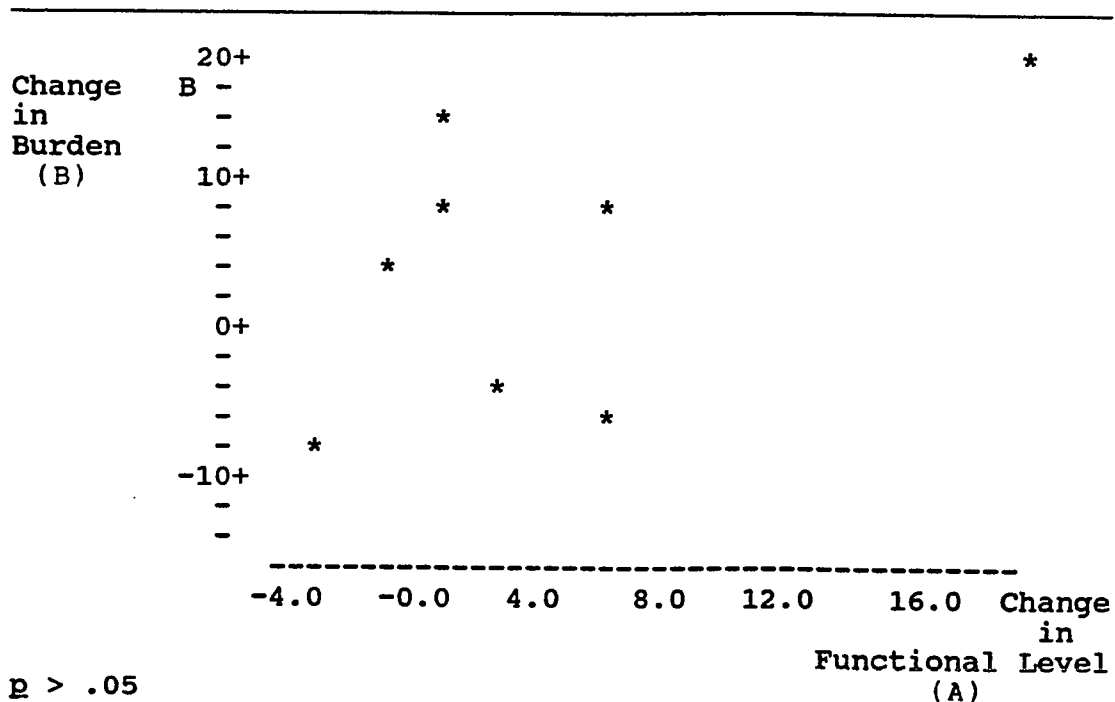
Alzheimer's client's Activities of Daily Living score over the 6 month period. Change in B represents the change in caregiver Burden scores over the 6 month period. This plot represents each of the 8 subjects' change in burden as related to their change in ADL or functional level.

The raw scores themselves did not demonstrate any trend toward correlation. They indicated that 3 out of 8 clients had increased ADL scores but no increase in Burden scores. One client had increased ADL scores with increased Burden scores. Two clients had decreased ADL scores and no change in Burden scores. Two had no change in ADL scores, and an increase in Burden score. The Pearson product moment correlation statistic, applied to change in Burden score related to change in ADL score, resulted in a coefficient of  $r = .597$  ( $p > .05$ ). No statistically significant

correlation was demonstrated between burden level and functional level, thus supporting the third research hypothesis.

Figure 1

Correlation Between Change in Caregiver Burden Level and Change in Client's Functional Level Following 6 Months of Alzheimer's Day Care. (N = 8)



It was interesting that in 5 out of 8 cases (62%), burden level was unchanged, despite the fact that in 3 cases the client's functional level decreased, requiring increased assistance from the caregiver.

These data suggested that the amount of stress and burden a caregiver experiences cannot be assumed based only on the functional level of the Alzheimer's client in a day

care program. It was suggested that factors not measured, such as additional respite time, amount and kind of social and family support may have had an effect on caregiver burden.

#### Individual Item Analysis

The following section analyzes and interprets individual item results from the Burden Interview and the A.D.C. ADL/IADL tool. The 8 responses to each of the 22 questions on the Burden Interview were tallied and given a mean score. The same was done for each question of the A.D.C. ADL/IADL tool. A ranking of mean scores for each individual question was done and examined to identify trends that may have clinical significance. Caregivers rated items 7, 8, and 14 of the burden interview the highest on the initial and 6 month follow up interviews. Item #7 had mean scores of 2.88 and 2.88 and stated, "Are you afraid of what the future holds for your relative?" Item #8 had mean scores of 3.75 and 3.88 and stated, "Do you feel that your relative is dependent upon you?" Item #14 had mean scores of 2.25 and 3.0 and stated, "Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?" (Zarit, et al., 1985, p. 84). Items that demonstrated the greatest increase over the 6 months were items #12 and 14 (just described). Item #12 stated, "Do you feel that your social life has suffered

because you are caring for your relative?" (Zarit, et al., 1985, p. 84).

Caregivers rated items 1, 4, and 5 the lowest. Item #1 mean scores were .88 and .5, and stated, "Do you feel your relative asks for more help than he/she needs?" Item #4 mean scores were .75 and .75, it stated, "Do you feel embarrassed over your relative's behavior?" Item #5 received mean scores of .63 and 1.0 and stated, "Do you feel angry when you are around your relative?"

These data suggested that caregivers felt very alone in their role as caregiver; that they felt increasingly isolated as the client became more dependent upon them and their ability to participate in social activities decreased. Caregivers felt the client's dependence upon them, but not without reason. A stressor for caregivers seemed to be the uncertainty over the client's future. Finally, these data suggest that the stressors and burden experienced by caregivers may be reflected more in feelings of isolation and responsibility rather than anger or embarrassment. It seemed to suggest caregivers had a certain understanding of Alzheimer's disease.

#### Functional Level

Individual item mean scores on the A.D.C. ADL/IADL Tools indicated caregivers found clients required most assistance with bathing (2.25 and 2.75), dressing (2.13 and



2.63), and grooming (2.25 and 2.50). Clients required least assistance in mobility, both inside and outside (1.25 and 1.25).

All of the eight instrumental activities of daily living categories--shopping, meal preparation, housework, laundry, telephone, transportation, money management, and medications--had mean scores that were much higher than the ADL mean scores. Most had means of 4.5-6.0. This suggests that the clients at day care required maximum assistance with all of these social skills.

## Chapter 5

### CONCLUSIONS AND RECOMMENDATIONS

Following 6 months of Alzheimer's day care for the client, caregivers' Burden scores were unchanged in the majority of cases. Mean scores of the Burden Interviews did not change significantly over the 6 month period. These data supported the first research hypothesis that the caregiver burden level did not differ following 6 months of day care. The data suggested that Alzheimer's day care may have had a positive effect on these caregivers by preventing increased burden levels. As Alzheimer's disease is a disease of progressive deterioration and need for increased care, day care may have served to strengthen caregivers lines of resistance and defense, preventing increased burden. It is recognized by the researcher that 6 months of study with a small sample could only provide preliminary data on caregiver burden, and that a longer study period with a larger number of respondents would be necessary to fully explore this question.

Following 6 months of Alzheimer's day care, mean scores of the Alzheimer's Day Care Activities of Daily Living Tool did not change significantly, supporting the second research hypothesis that the functional level of the Alzheimer's client would not differ following 6 months of day care. The data suggested that Alzheimer's day care, by providing a structured activity program for clients, may have assisted

in the maintenance of their functional abilities, a stated goal of many centers reviewed in the literature. It was interesting that in two cases functional abilities actually improved, considering the expected course of deterioration found with Alzheimer's disease. It is unknown but possible that functional level would have decreased to larger degrees without the intervention of day care.

No statistically significant correlation was found between the functional abilities of the clients and the burden levels of the caregivers, supporting the third hypothesis. While no relationship was demonstrated between functional ability of the client and burden level of the caregiver, raw scores did show that in 3 out of 4 cases where functional abilities decreased, burden level of their caregivers remained stable. These data suggest that the intervention of Alzheimer's day care may have prevented increased burden in these cases.

The individual item analysis suggested the stresses of social isolation, uncertainty and totality of responsibility for the Alzheimer's client may have the most bearing on the caregiver burden. These data showed Alzheimer's clients required maximum assistance with all instrumental activities of daily living, and moderate assistance with bathing, grooming, and dressing.

### Recommendations

Based on the literature review conducted for this study and on the findings of this preliminary study, certain recommendations for research and nursing practice are offered. First, it is recommended that the study be repeated with a larger sample size. Trends and patterns in the data would be clearer and findings more generalizable with a larger sample size. One suggestion would be to study results of Burden Interviews and Activity of Daily Living Scores from all the present Alzheimer's Day Care Resource Centers in California associated with the pilot project started in 1984 by the State Department of Aging. Another recommendation would be to study the larger sample, discussed above, over a longer time interval (1 to 2 years). This would provide more information on changes in functional level and burden over time. Findings could be more conclusive.

If the study is replicated, it is recommended that the day care centers administer a depression scale, such as the Zung Depression Status Inventory (Bellack & Bamford, 1984, p. 158) to caregivers along with the Burden Interview. This currently is not being done. The developer of the Burden Interview, (Zarit, et al., 1985) suggests that a measure of caregiver depression be taken when administering the Burden Interview as burden is not the only measure of the caregiver's emotional state.

It is recommended that the nursing profession increase its involvement in adult day care for Alzheimer's clients. Adult day care is a relatively new setting for Alzheimer's clients. It is also a new setting for the nursing profession. It is a setting where nurses can use all components of the nursing process to assist clients and their families to attain maximum wellness and client system stability. Interventions that nurses can provide in this setting include assessment and evaluation of: medications, general health, nutritional status, behavior, self-care and functional ability, and of specific care needs. Nurses can work with families and clients to plan appropriate interventions. They can provide valuable education, support, and referral for families. Interventions suggested by this researcher include increasing respite time for caregivers for social and personal activities; increasing family and/or significant others' involvement with the Alzheimer's client to relieve primary caregiver of responsibility, instruction on bathing, grooming, and behavior management for the client with Alzheimer's disease. Based on the preliminary findings of this study, these interventions may affect the impact stressors associated with caregiving may have on caregivers. The prevalence of Alzheimer's disease is expected to increase. It is important and timely that nurses take an active role in the management of this public health problem. As family

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caregivers continue to provide the majority of care for clients with the disease, nurses should address the problems and needs of family caregivers. Alzheimer's day care is a setting where nursing skills can be utilized to benefit both client and caregiver.

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**APPENDIX A**  
**HUMAN SUBJECTS APPROVAL WAIVER**

## Appendix A

## Human Subjects Approval Waiver

12/19/88

Irene Lewis  
Department of Nursing

Dear Irene,

I received your letter regarding Human Subjects Approval. I have clarified this issue with Dr. Serena Stanford AAVP/GS&R and am writing to provide written confirmation of the following. I have conferred with Dr. Stanford in regards to submitting my thesis to the Human Subjects Committee for review. As my thesis is a secondary data analysis only, and data when collected was assigned a number, which was what I utilized for the analysis, Dr. Stanford concluded that submission to the Human Subjects Committee is not needed in this case. She suggested this letter be written so that all parties will be informed.

Sincerely, *Rachel Holz*

*Accurately stated.*

*Serena Stanford*  
*12/22/88*

RECEIVED  
DEC 23 1988  
GRADUATE STUDIES  
San Jose State University

**APPENDIX B**  
**BURDEN INTERVIEW**

## Appendix B

## Instructions for the Burden Interview

The Burden Interview has been specially designed to reflect the stresses experienced by caregivers of dementia patients. It can be completed by caregivers themselves or as part of an interview. Caregivers are asked to respond to a series of 22 questions about the impact of the patient's disabilities on their life. For each item, caregivers are to indicate how often they have felt that way, never, rarely, sometimes, quite frequently, or nearly always.

## SCORING:

The Burden Interview is scored by summing the responses of the individual items. Higher scores indicate greater caregiver distress. The Burden Interview, however, should not be taken as the only indicator of the caregiver's emotional state. Clinical observations and other instruments such as measures of depression should be used to supplement this measure.

Norms for the Burden Interview have not been computed, but estimates of the degree of burden can be made from preliminary findings. These are:

0 - 20	Little or no burden
21 - 40	Mild to moderate burden
41 - 60	Moderate to severe burden
61 - 88	Severe burden

**PLEASE NOTE:**

Copyrighted materials in this document have not been filmed at the request of the author. They are available for consultation, however, in the author's university library.

These consist of pages:

66-68

**U·M·I**

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APPENDIX C  
ALZHEIMER'S DAY CARE RESOURCE CENTER  
ACTIVITIES OF DAILY LIVING/INSTRUMENTAL ACTIVITIES  
OF DAILY LIVING ASSESSMENT TOOL  
(ADL/IADL)

## Appendix C

### Instructions for ADL/IADL and LSRI

THIS INSTRUMENT WILL BE USED TO COMPLETE BOTH THE ADL/IADL ASSESSMENT AND THE LEVEL OF SEVERITY INSTRUMENT (LSRI).

#### ADL/IADL

The ADL/IADL and LSRI assessments are done for every patient at the time of the initial assessment and when there is a status change or a reassessment of the patient. The ADL/IADL and LSRI are part of the patient data set and should be completed when PART 1 and PART 2 of the patient data set are collected.

To complete the ADL/IADL and LSRI assessment, use the instrument provided. For each activity circle the number and letter that corresponds to the statement that best describes the patient, then place that number on the line provided to the right side of the page above the letter N; and place the letter above the letter L (see the example below).

#### EATING/FEEDING

1. Feeds self without help of any kind (L)
2. Feeds self with help of device (L)
3. Feeds self with help of another person (M)
4. Feeds self with help of another person and a device (M)
5. Is spoon fed (S)
6. Is tube and parentally fed (S)

The patient's ADL score will be the sum of the numbers given to the activities in the ADL section. The IADL score will be the sum of the numbers given to the activities in the IADL section. Write the scores on the first page of the instrument, and fill out the patient's number and the data of assessment.



Activities of Daily Living (ADL) and Instrumental

Activities of Daily Living (IADL)

Patient Number \_\_\_\_\_ Date of Assessment \_\_\_\_\_  
 ADL Score \_\_\_\_\_ IADL Score \_\_\_\_\_

ACTIVITIES OF DAILY LIVING (ADL)

EATING/FEEDING

1. Feeds self without help of any kind (L)
2. Feeds self with help of device (L)
3. Feeds self with help of another person (M)
5. Is spoon fed (S)
6. Is tube and parentally fed (S)

\_\_\_\_\_ N \_\_\_\_\_ L

TRANSFER

1. Transfers without help of any kind (L)
2. Transfers with help of equipment or device (L)
3. Transfers with help of another person (M)
4. Transfers with help of another person and equipment (M)
5. Is transferred (does not participate) (S)
6. Is not transferred (bed fast) (S)

\_\_\_\_\_ N \_\_\_\_\_ L

MOBILITY/WALKING -- OUTSIDE

1. Walks without help of any kind (L)
2. Walks with help of mechanical supports (no personal help) (L)
3. Walks with the assistance of another person (no mechanical help) (M)
4. Walks with help of both mechanical and personal assistance (M)
5. Does not walk (possibly carried) (S)
6. Bedridden more than half the time (S)

\_\_\_\_\_ N \_\_\_\_\_ L

MOBILITY/WALKING -- INSIDE

1. Walks without help of any kind (L)
2. Walks with help of mechanical supports (no personal help) (L)
3. Walks with the assistance of another person (no mechanical help) (M)

ADCRC Code/Patient ID Number \_\_\_\_/\_\_\_\_

4. Walks with help of both mechanical and personal assistance (M)
5. Does not walk (possibly carried) (S)
6. Bedridden more than half the time (S)

N \_\_\_\_\_ L

#### DRESSING

1. Dresses, undresses and selects own clothing -- needs no assistance (L)
2. Dresses and undresses but requires assistance selecting clothes (L)
3. Requires some assistance always dressing and undressing (M)
4. Needs major assistance, but cooperates with efforts of others to help (M)
5. Needs major assistance, and resists efforts of others to help (S)
6. Refuses to change clothes (S)

N \_\_\_\_\_ L

#### GROOMING (neatness, hair, face, hands, nails, etc.)

1. Always acceptably groomed without assistance (L)
2. Needs minor assistance in grooming, and occasional reminders (L)
3. Needs regular supervision or assistance in grooming (M)
4. Needs total grooming care, but remains interested in staying well-groomed (M)
5. Needs total grooming care, but is not interested in maintaining grooming and sometimes resists and negates efforts of others (S)
6. Refuses any grooming (S)

N \_\_\_\_\_ L

#### BATHING

1. Bathes without assistance or reminders (L)
2. Bathes self but requires reminding (L)
3. Washes hands and face but cannot bathe rest of body (M)
4. Cannot bathe self but accepts assistance (M)
5. Cannot bathe self and resists assistance (S)
6. Refuses to be bathed (S)

N \_\_\_\_\_ L

ADCRC Code/Patient ID Number     /

## TOILETING

1. Uses toilet room without help of any kind (L)
2. Needs to be reminded or needs help in cleaning self (L)
3. Uses a bedpan or urinal (no personal help) (M)
4. Uses toilet room with help of a person (no bedpan) or urinal (M)
5. Uses toilet room with help of a person and also uses a bedpan or urinal (S)
6. Does not use toilet room (S)

N  L

## CONTINENCE CARE

1. Full control of bowel and bladder function (L)
2. Has occasional urinary accident (L)
3. Soiling or wetting while asleep more than once a week (M)
4. Soiling or wetting while awake more than once a week (M)
5. Either gets personal help or has frequent accidents or is catheterized (S)
6. No control of bowels or bladder (S)

N  L

ADCRC Code/Patient ID Number \_\_\_/\_\_\_ \_\_\_

INSTRUMENTAL ACTIVITIES OF DAILY LIVING (IADL)

## SHOPPING

1. Shops without difficulty or advice (L)
2. Shops independently for small purchases (milk, cookies, shoes) (L)
3. Requires assistance making decisions (M)
4. Has lost interest in shopping but tags along (M)
5. Unable to tag along (S)
6. Refuses to go shopping at all (S)

	<hr style="width: 100%;"/>
	N L

## MEAL PREPARATION

1. Prepares meals without any difficulty or advice (L)
2. Requires assistance in planning and preparation (L)
3. Forgets recipes and ingredients (M)
4. Able to make cup of coffee or tea, but that's all (M)
5. Loses track of meal hours (S)
6. Unable to heat and/or serve a meal (S)

	<hr style="width: 100%;"/>
	N L

## HOUSEWORK

1. Does all light and heavy housework without personal help (L)
2. Does all light housework without personal help (L)
3. Gets personal help with some light housework (M)
4. Gets personal help with all housework (M)
5. Unable to do any housework (S)

	<hr style="width: 100%;"/>
	N L

## LAUNDRY

1. Does all laundry without personal help (L)
2. Does most laundry without personal help (L)
3. Launders only small items without personal help (M)
4. Launders only small items with personal help (M)
5. Does not do any laundry (S)

	<hr style="width: 100%;"/>
	N L

ADCRC Code/Patient ID Number \_\_\_/\_\_\_ \_\_\_

**TRANSPORTATION**

1. Drives a private auto (L)
2. Never needs personal help even when traveling on public transportation (L)
3. Sometimes needs personal help if traveling on public transportation but never needs personal help when traveling in taxi/private auto (M)
4. Always needs personal help if traveling on public transportation and sometimes needs personal help when traveling in taxi/private auto (M)
5. Travels only in taxi or private auto and always needs personal help (S)
6. Does not travel (S)

	<hr style="width: 100%;"/>
	N                      L

**TELEPHONE**

1. Has no problem noting calls, finding numbers (L)
2. Can make calls but needs assistance with numbers (L)
3. Requires assistance dialing (M)
4. Answers phone and takes messages (M)
5. Answers phone but cannot take messages (S)
6. Doesn't use telephone at all (S)

	<hr style="width: 100%;"/>
	N                      L

**MEDICATIONS**

1. Does not take medications (L)
2. Takes own medications without any personal help (L)
3. Takes own medications with some personal help (M)
4. Medications taken care of totally by others (M)
5. Refuses to swallow or spits it out (S)
6. Refuses medicine when offered (S)

	<hr style="width: 100%;"/>
	N                      L

**MONEY MANAGEMENT**

1. Manages money, checkbook and banking without difficulty (L)
2. Manages money, checkbook and banking with difficulty (L)
3. Handles day-to-day purchases but requires help with major ones (M)
4. Requires assistance writing checks, paying bills, banking (M)

ADCRC Code/Patient ID Number \_\_\_/\_\_\_ \_\_\_

5. Makes frequent errors with cash and counting change (S)
6. Has given up all financial matters (S)

---

N L

**APPENDIX D**  
**APPROVAL TO USE**  
**PRIMARY DATA**

Appendix D  
Approval to Use Primary Data

August 2, 1988

To Whom it may concern:

Rachel Holz has received appropriate approval from administration and caregivers to use data collected at the Monterey County Alzheimer Day Care Center for scholastic purposes.

Sincerely,

A handwritten signature in cursive script that reads "Ardith Breton". The signature is written in black ink and is positioned above the typed name.

Ardith Breton MA, OTR

Director A.D.C.R.C.