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Female caregivers of elderly relatives with dementia : implications for day center intervention

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Implications for day center intervention**

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San Jose State University, 1991

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FEMALE CAREGIVERS OF ELDERLY RELATIVES
WITH DEMENTIA: IMPLICATIONS FOR
DAY CENTER INTERVENTION

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

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May, 1991

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ABSTRACT

FEMALE CAREGIVERS OF ELDERLY RELATIVES WITH DEMENTIA: IMPLICATIONS FOR DAY CARE CENTER INTERVENTION

by Betty S. Baldwin

An ex post facto descriptive design was used to study the effectiveness of day center intervention as a means of increasing coping skills of female caregivers of elderly relatives with dementia. The study was a secondary analysis of data from a related study. Data were collected from caregivers who were using the services of a day center in providing care for an elderly relative with dementia. The center provides emotional support, educational, resource, and referral services for the caregivers. A combination of Dorothea Orem's self care model and Hans Selye's stress concepts form the conceptual framework for this study. Each respondent completed four standardized assessment tools, a respondents profile and three impact questions. The impact questions focused on the caregivers' perceived coping skills before and after day center intervention. Findings show a significant increase in perceived coping skills after day center intervention.

Dedicated
to
The Loving Memory
of
My Husband

Curtis L. Baldwin

Who was always supportive
of my educational endeavors

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Chapter 1

INTRODUCTION

Research on family caregivers suggests that family members who care for elderly relatives with dementia are at risk for deterioration in health, general well-being, social activities, and financial status (Brody, 1981; Caserta, Lund, Wright & Redburn, 1987; Gallagher, Rose, Rivera, Lovett, & Thompson, 1989; Zarit, Orr, & Zarit, 1985). In addition, research indicates that the bulk of long-term care is not provided by institutions, but in the home by family members (Caserta, et al., 1987).

The burden of home care is compounded by the fact that the primary caregivers are frequently older women, spouses, daughters, or daughters-in-law, who themselves have health problems (Brody, 1981). Caregivers routinely report stress-related symptoms, such as anxiety, depression, or feelings of fatigue. They are often angry, resentful or feel guilty about not doing enough, even though they may spend 24 hours a day with the elderly relative with dementia (Zarit, Orr & Zarit, 1985, p. 69). Additional data on the burden, and risk factors including stress and depression in relation to female caregivers of relatives with dementia, will be presented in subsequent sections of this study.

The present study is a secondary analysis of data from a previous study (Lewis, 1987) to investigate the supportive

impact of an intervention, a day center, on primary family caregivers' coping skills. The goal of Lewis' study (1987) was to determine the influence a day center has upon easing the burden for male and female caregivers of elderly relatives with dementia and thereby decreasing negative physical, emotional, and social outcomes for the caregiver. Data for Lewis' study (1987) were collected from male and female family caregivers including spouses, daughters, daughters-in-law, and other relatives, who utilized the services of a day center in caring for an elderly relative with dementia. All respondents were 18 years of age or older.

The present study was conducted to further explore the influence of a day center as a means of decreasing negative effects of caregiving for female family caregivers. The current research focused on the effect of a day center intervention on female family caregivers' coping abilities and level of depression. The study examined data collected from female respondents in the study conducted by Lewis (1987).

The Problem and Research Questions

Data on female caregivers (Archbold, 1983; Brody, 1981; Crossman, 1981; Fengler, 1979; Hooyman & Lustbader, 1986, p. 91) suggest that female family caregivers experience burden which contributes to stress, depression and decreased

social contacts. In addition, the burden is particularly onerous when the care is for a relative with a diagnosis of dementia. Although individual caregivers experience the burden of caring for relatives with dementia in different ways, the overall problem contributes to physiological, psychological and sociological stress (Brody, 1981; Demling & Bass, 1986).

Gallagher, Lovett, and Zeiss (in press) have identified four conceptually distinct types of intervention based on the nature of the services available. The four categories include respite programs, peer-led support groups, professionally-led educational support groups, and counseling/psychotherapy. Day center intervention, the focus of this study, fits into the category of respite programs.

Research Questions

Day center intervention is designed to provide support/education and relief for the caregiver and a structured program for the care recipient. This study assessed the following research questions:

1. Will female caregivers report increased coping abilities for caring for an elderly relative with dementia after day center intervention?

2. How will female caregivers using a day center intervention score on the Zung Depression Status Inventory (DSI) scale?

Hypotheses

This study tested the following hypotheses:

1. Through participation in a day center, female caregivers will increase their coping skills.
2. Female caregivers using a day center intervention will achieve scores below 61 on the Zung Depression Status Inventory Scale.

Purpose and Need

The purpose of this study was to assess the impact of an intervention, a day center, on the coping skills of female caregivers for elderly relatives with dementia. While numerous studies have focused on the burden and stress experienced by caregivers, few have focused on intervention programs (Katz, Gallagher, Zielski, & Bruguera, 1987). In addition, there is an even greater sparsity of studies related to the caregivers' response to these programs. In view of the increasing number of elderly persons being cared for in the home and the multiple responsibilities of female relatives providing care, the development of relevant respite programs is vital. Input from female caregivers should be an integral component in the planning, implementation, and evaluation of any respite program. The

most important factor in deciding the direction of intervention is what help the caregivers want for themselves and for the care recipient (Zarit, Orr, & Zarit, p. 83, 1985).

Definition of Terms

For the purpose of this study the following conceptual definitions apply:

1. Agent is the person taking action to provide self-care. (Orem, 1980, p. 35).
2. Care recipient is a person requiring supervision and assistance with activities of daily living due to mental and/or physical disability (Stone, Cafferata, Sangl, 1987).
3. Caring is a concept encompassing that range of human experiences which have to do with feeling, concern for and taking charge of the well-being of others (Graham, 1983, p. 13).
4. Coping is the use of strategies to reduce the negative effects of stress (Lewis, 1987).
5. Day Center is a facility that provides a structured program for elderly persons with Alzheimer's disease and related disorders. Activities include reminiscence groups, current events, arts and crafts, music, and outings as well as medical and psychiatric care. In addition, supportive-education, counseling and referral services are provided for family caregivers (Lewis, 1987).

6. Dementia is a syndrome of progressive impairment of memory and other cognitive abilities (Zarit, Orr & Zarit, 1985, p. 9).

7. Dependent-care agent is the provider of infant care, childcare, or dependent adult care (Orem, 1980, p. 35).

8. Elderly are those individuals aged 65 years and older (Yurick, Spier, & Ebert, 1989, p. 784).

9. Family caregivers are generally daughters and wives, but also husbands and sons who provide care for an elderly family member who has some degree of physical, emotional, or economical impairment (Harowitz, 1985).

10. Frail elderly are those older persons who have such social, economic, physical or mental limitations that help is required from family, friends, or social agencies to perform the ordinary tasks of daily living (Yurick, Spier, Robb, & Ebert, 1989, p. 785).

11. Primary caregiver is the person providing day-to-day physical and supportive care for a disabled person (Stone, Cafferata & Sangl, 1987).

12. Self-care is the practice of activities that individuals initiate in maintaining life, health, and well-being (Orem, 1971, p. 15).

13. Self-care agent is the provider of self-care (Orem, 1980, p. 35). Performs actions which contribute to

human structural integrity, human functioning, and human development (Orem, 1980, p. 37).

14. Self-care requisites are the purposes to be attained through self-care actions (Orem, 1980, p. 37).

15. Stress is the non-specific response of the body to any demand (Selye, 1976, p. 55).

16. Stressor is that which produces stress.

Research Design

This study utilized an ex post facto descriptive design. Ex post facto means "from after the fact" (LoBiondo-Wood & Haber, 1986, p. 132). The one-shot group that has been exposed to some prior treatment (independent variable) is referred to as a descriptive study (Huck, Comier & Bounds, 1974, p. 227). The design was appropriate for the study because it did not employ random assignment or use a control group. In addition, the independent variable, day center intervention, was not manipulated. The caregivers were using the services of the center at the time of data collection. The current study is a secondary analysis of data from a study (Lewis, 1987) conducted to measure the supportive impact of an intervention, a day center, on male and female primary family caregivers.

Data Analysis

An ex post facto descriptive design was used to investigate the effect of day center intervention on

perceived coping skills of female caregivers of elderly relatives with dementia. The study focused on the female caregivers' use of day center intervention as a means of reducing stress and depression. Descriptive statistics were used to analyze data. The analysis process included frequencies, means, standard deviations and histograms of caregivers' characteristics. Also, student t-tests were used to ascertain differences in caregivers' perceptions before and after the day center intervention.

Scope and Limitations

The scope of this study was limited to an investigation of the supportive impact of day center intervention on female primary family caregivers. The respondents were primary caregivers for relatives with dementia who utilized the services of a local day center. The study examined data collected from female respondents from Lewis' (1987) study.

Several limitations are inherent in an ex post facto descriptive design. The absence of a control group is a major limitation. Additional limitations include the use of a pre-existing group and the lack of pretest data. Further, there is no opportunity for the researcher to apply random sampling or manipulate the independent variable.

Chapter 2

CONCEPTUAL FRAMEWORK AND REVIEW OF RELATED LITERATURE

This section will present a general overview of two conceptual models (See Appendix A) with emphasis on components that are relevant to this study. The relevant components will be used to address coping in relation to quality of life for female caregivers who used a day center intervention for a relative with dementia. A review of related literature is also included in this section.

Conceptual Framework

Female caregivers of elderly relatives with dementia frequently become so involved in caring for the care recipient that they neglect their own physiological, psychological and sociocultural well being (Archbold, 1983; Brody, 1981; Crossman, London, & Barry, 1981). Numerous studies (Demling & Bass, 1986; Fengler & Goodrich, 1979; Gallagher, Rose, Rivera, Lovett, Thompson, 1989; Zarit, Orr, Zarit, 1985, p. 69) reported findings which suggest that caring for elderly relatives with dementia often results in decreased perceptions of well-being and increased feelings of stress and depression. In view of these findings, the conceptual framework for this study was derived from the concepts of self-care and the body's response to stress. The combination of the supportive-education system of Orem's (1980, p. 101) self-care conceptual framework and Selye's

(1976, p. 367) theory of human stress provided an appropriate structure for the investigation of female caregivers' perception of burden and stress after utilization of a day center intervention.

Orem's Self-Care Conceptual Framework

The primary focus of Orem's conceptual framework is to move the individual toward responsible self-care. Orem (1980, p. 35) defines self-care as the production of actions directed to self or to the environment in order to regulate one's functioning in the interest of one's life, integrated functioning, and well-being. This definition of self-care suggests that it is a practical response to an experienced demand to attend to oneself. The demand may originate in the individual or in the environment. Orem's conceptual framework is based on the general theory that "people can benefit from nursing because they are subject to health-related or health derived limitations that render them incapable of continuous self-care or dependent care or that result in ineffective or incomplete care" (p. 27).

Orem's conceptual framework includes three theoretical constructs (p. 26). The first construct is that self-care deficits and deficits for dependent care, are predictive of nursing requirements. It provides criterion measures for those who need nursing as well as when and why nursing is needed. The second construct is that self-care and

dependent care are systematized, deliberate actions that, when continuously and effectively engaged in, regulate structural integrity, human functioning, and human development. The third construct is that the product of nursing practice is a nursing system through which the capability of patients to engage in self-care is regulated and self-care is continuously produced.

In addition, Orem's conceptual framework includes three types of nursing systems which specify self-care actions that can be performed by either nurses or clients or nurses and clients. The three types of nursing systems are described as wholly compensatory, partly compensatory, and supportive educative (Orem, 1980, p. 96). Under the wholly compensatory system the client has physiological or psychological limitations for controlled movement in the accomplishment of required self-care. Under the partly compensatory nursing system the client has a self-care requisite to limit energy expenditures because of health state. The supportive-educative system is for situations where the client is able to perform or can and should learn to perform required measures of externally or internally oriented therapeutic self-care but cannot do so without assistance.

The central requisites for self-care are learning and the use of knowledge in performing externally or internally oriented sequences of self-care actions (Orem, 1980, p. 213). Likewise, the body's response to stress reflects internal as well as external factors. The conceptual framework of this study addresses these factors through a combination of Orem's concept of self-care and Selye's concept of stress.

Selye's Stress Concept

The review of literature suggest that female caregivers of relatives with dementia experience burden and stress due to feelings of isolation, embarrassment, anxiety about going out socially with or without the care recipient, anger, resentment, frustration, and restriction on activities. Selye's stress concept helps explain the body's reaction to stress including coping resources.

Selye (1976, p. 398) defines stress as the non-specific response of the body to any demand including efforts to cope with the wear and tear on the body caused by life at any one time. However, he explains that although stress is non-specifically induced, it shows itself as a specific syndrome. The stress response is non-specific because it can be produced by virtually any agent. However, the pattern of the stress reaction is specific. It affects

certain glands and organs, including the adrenal, the thymus and the gastrointestinal tract.

The body's response to stress is determined by internal and external conditioning. Hereditary disposition, previous experience, and physical condition are examples of internal conditioning. Examples of external conditioning include food ingredients, atmospheric pollutants and contacts with other people (p. 370). According to Selye (p. 370) the most important stressors in life are emotional, especially those causing distress.

Selye (1956, p. 274) developed a model that helps explain the course of biological decompensation under excessive stress. This model has been incorporated into Selye's (p. 274) general adaptation syndrome. The premise of general adaptation syndrome is that the body's reaction to sustained and excess stress typically occurs in three major stages: (a) alarm and mobilization which represents a general call to arms of the body's defensive forces; (b) stage of resistance in which biological adaptation is optimal in terms of bodily resources; and (c) exhaustion and disintegration in which bodily resources are depleted and the organism loses its ability to resist so that further exposure to the stress can lead to disintegration and death. However, Selye (1976, p. 456) offers the assurance that appropriate intervention can effectively diminish the wear

and tear of stress and improve the quality of life. In addition, Selye (p. 452) offers guidelines for enhancing one's coping abilities. These guidelines include self-analysis to establish what you really want, avoidance of social isolation, and being supportive of others. Further, Selye (p. 407) suggests that recognition of the body's physiological and psychological responses to stress can help an individual maintain or regain balance in stressful situations. These guidelines are applicable to female caregivers who experience the burden and stress of caring for an elderly relative with dementia.

Application of Orem's Self-Care

Concept and Selye's Stress Concept

The combination of Orem's self-care conceptual framework and Selye's concept of stress has implication for the planning and delivery of service for female caregivers who use a day center intervention for elderly relatives with dementia. This combination provides a structure that can be used to encourage female caregivers to analyze the stressors in their lives and evaluate the effectiveness of a day center intervention in helping them cope with identified stressors. In addition, it can be used to assist female caregivers in acquiring self-care skills for coping with the burden and stress of caring for an elderly relative with dementia. The acquisition of these skills would have the

potential of improving the quality of care for the elderly relative with dementia as well as enhancing the quality of life for the caregiver.

Related Literature

The literature was reviewed to become familiar with available material and studies related to this study, to review the data from previous studies and to determine the current status of research relating to this problem. The primary focus of this review was female caregivers of elderly relatives with dementia. In addition, the review explored the physiological, psychological, and socio-cultural aspects of caregiving and day care intervention.

Data from several studies (Eskew, Sexton, Tars, Wilcox, 1983; Katz, Gallagher, Zielski, Buguera, 1987; Pierotte, 1977; Sands & Suzuki, 1983) suggest that day center intervention decreases caregivers' feelings of burden, stress and depression. In addition to providing relief to female family caregivers, day center intervention may be effective in allowing the care recipient to remain in the community (Harowitz, 1985; Miller & Gulle, 1985; Sands & Suzuki, 1983).

Alzheimer's Disease has been identified as the common cause of severe dementia in this country. It is estimated that between 1.5 to 2 million Americans are currently suffering from the disease (Muwaswes, et al., 1989). Recent

interest in elderly with Alzheimer's Disease has focused attention on the heavy burden carried by relatives who provide the care which allows persons with dementia to remain in the community.

Data reveal that 80 to 90 percent of disabled older people are cared for in the home (Sommers & Shields, 1987). There is evidence that the primary care is not shared equally among all family members. Data from several studies (Brody, 1981; Nowak, 1986; Robinson, 1985; Seixas, 1988) suggest that care of the elderly is primarily provided by females who are spouses, daughters or daughters-in-law of the care recipient.

Brody, Kleban, Johnsen, Hoffman and Schoonouer (1987) reported that female caregivers experienced competing familial, employment, and social demands. According to Sommers and Shields (1987), caregivers with children at home face two generations with conflicting needs for nurturance. The conflict is compounded for the increasing number of female caregivers who work outside the home. Brody, Kleban, Johnsen, Hoffman, and Schoonouer (1987) observed that when female caregivers are confronted with competing demands on their time and energy, they give up their own free time and opportunities for socializing.

Several investigators (Baillie, Norbeck & Barnes, 1988; Haley, Levine, Brown, Berry & Hughes, 1987; Demling & Bass,

1986) have studied the physiological, psychological, and sociocultural aspects of caregiving. Data from these studies suggested that primary caregivers of dementia patients are at risk for physical problems, psychological distress and depression.

Data from several studies (Caserta, Lund, Wright & Redburn, 1987; Fisk, 1983; Hooyan & Lusbader, 1986; Zarit, Orr, & Zarit, 1985) suggested that primary caregivers are frequently older women who themselves have health problems. According to Aronson and Lipkowitz (1981) spouse caregivers who are elderly and have a fixed marginal income are particularly at risk.

Caregivers of elderly relatives with dementia are frequently burdened with the responsibility of providing multiple services for the care recipient. Some of the most common responsibilities include physical care, financial management, management of problem behavior, and emotional support (Katz, Gallagher, Zielski, Burguera, 1987). In addition, Sands and Suzuki (1983), reported that when the person giving care lacks support, the problem of being effectively confined to the home can lead to agitation in the care recipient.

Several studies (Fengler & Goodrick, 1979; Katz, Gallagher, Zielski, & Bruguera, 1987; Miller & Gulle, 1986; Sands & Suzuki, 1983), report findings which suggest that

day center intervention has the potential of being beneficial to the caregiver as well as the care recipient. Benefits reported by the various studies included emotional support, "time-out" from the burden and stress of providing care, educational support regarding the care recipients' impairment and management of inappropriate behavior. In addition, studies (Crossman, London, & Barry, 1981; Eskew, Sexton, Tars & Wilcox, 1983) reported findings which suggest that day center intervention has the potential for providing an alternative to institutionalization or at least increasing the length of time that the care recipient can be cared for at home.

Quayhagen and Quayhagen (1989) conducted a study to investigate the effects of therapeutic intervention for dementia patients and their caregivers. Data from the study support benefits to both care recipients and caregivers who participate in a day center program. Results from a study by Haley, Levine, Brown, Berry, and Hughes (1987) support the importance of providing comprehensive services for caregiving families.

Orem's (1971, p. 37) self-care conceptual framework provides guidelines for interventions that are appropriate for caregivers as well as care recipients. The central idea of Orem's (p. 28) self-care theory is that self-care and care of dependent family members are learned behaviors that

purposely regulate human structural integrity, human functioning, and human development. In addition, Orem (1985, p. 35) suggests that the individual's ability to engage in self-care or dependent-care are conditioned by age, developmental state, life experience, sociocultural orientation, health, and available resources. The day center intervention provided caregivers an opportunity to participate in self-care through utilization of respite, counseling, and supportive-educative services.

Selye's (1976, p. 370) concept of stress is compatible with Orem's self-care conceptual framework. Selye's theory of human stress suggests that human stress is mediated by stress energy that enables one to handle that stress. According to Selye (1976) healthy life and hemostasis can be achieved through employing physiological and psychological techniques.

Zarit, Orr, and Zarit (1985, p. 89) developed a model which addresses stress from the perspective of the caregiver as well as the care recipient. The model is specifically designed for caregivers of patients with dementia. The treatment strategies of this model were designed to improve the caregivers' ability to manage problems. In addition, Zarit, Orr, and Zarit (1985, p. 84) developed the Burden Interview. This instrument evaluates the caregivers'

subjective burden. It was utilized in the data collection process for this study.

Summary

The review of literature suggests that caregivers of relatives with dementia are at risk for physiological, psychological, and sociocultural stress. Further, there is evidence that the care is not shared equally among family members. Care is primarily provided by female relatives (spouses, daughters, and daughter-in-law) of the care recipient. In addition, female caregivers experience competing familial, employment, and social demands. Day center intervention has been utilized as a coping strategy for elderly care recipients with dementia and their caregivers.

Chapter 3

THE METHOD

This section describes the research design, data collection techniques and process for analysis of the data used in this study. The study is a secondary analysis of selected data from a study conducted by Lewis (1987). Approval for access to the data from Lewis' (1987) study was granted in writing on June 2, 1989 (Appendix B). Permission to conduct the present study was granted by the San Jose State University Committee for the Protection of Human Subjects on January 22, 1990 (Appendix C).

The study examines the effects of day center intervention on the perceived coping abilities of females who are the primary caregivers for elderly relatives with dementia. In addition, the study examines the caregivers' scores on the Zung (1972) Depression Status Inventory (DSI).

Procedures

All data were collected at a day center for elderly persons with dementia. The day center is located in San Jose, California. Services provided by the day center include a structured program for elderly men and women with dementia. In addition, it provides support services for the primary caregiver which includes counseling, peer group interactions, resource information and referral. The day center is staffed by an administrator, a nurse practitioner,

a recreational therapist, an occupational therapist, instructional aides, a psychologist and volunteers.

Research Design

The study utilized an ex post facto descriptive design (LeBiondo-Wood & Haber, 1986, p. 132), to assess the effect of day center intervention on the coping skills of female caregivers of relative with dementia. Ex post facto literally means "from after the fact." The design is appropriate for this study because it was a one-shot study involving female caregivers who were using the services of the day center at the time of data collection. There was no opportunity for the researcher to create or manipulate the intervention. In addition, the study did not employ random assignment.

Data Collection

All data utilized in the current study were collected from the study conducted by Lewis (1987). Lewis' study used the following procedures. Permission to recruit potential respondents was obtained from the administrator of a day center for older adults with Alzheimer's disease and related disorders. In addition, approval to conduct the study was granted by the San Jose State University Committee for the Protection of Human Subjects (Appendix D). After approval had been obtained, an invitational letter which included a stamped return envelope, was mailed to all primary

caregivers who had relatives enrolled in the day center. Caregivers who chose to participate returned their signed acceptance form to the researcher.

A research assistant (RA) was recruited from the undergraduate nursing program to assist in the data collection process. The researcher conducted a total of sixteen hours of training with the RA. The training included teaching the RA how to introduce the study through a telephone contact, how to conduct the interview including administration of assessment tools, and how to score the Burden Interview and the Depression Status Inventory.

An invitation to participate in the study was mailed to all caregivers who used the services of the day center. The RA contacted interested and willing respondents by telephone and scheduled them for an interview. Data were collected during a one-time thirty minute interview conducted in a private office at the day center. Prior to conducting the interview, the RA explained the study, answered any questions and obtained a signed informed consent from the respondent.

Description of Assessment Tools

Lewis (1987) used four standardized assessment tools plus a Respondents Profile (Appendix E) to investigate the effect of day center intervention on caregiver's coping skill. Each respondent was asked to complete the assessment

tools in the following order: (a) Respondent's Profile plus three impact questions (b) Memory and Behavior Problems Checklist, (c) Activities of Daily Living, (d) Burden Interview, and (e) Depression Status Inventory.

The Respondents' Profile plus three impact questions (See Appendix E) were used to obtain basic socio-demographic information from the caregiver plus their perceptions on how they had benefitted or not benefitted from the day center intervention. The socio-demographic information included the caregivers age, sex, type of relationship between the caregiver and the care recipient, ethnicity (optional), educational background, employment status, living arrangements, religious preference and referral sources. In addition, there were questions related to the caregivers understanding of the care recipient's illness and reason for seeking help.

The three impact questions were designed to assess the caregivers perception of the impact of day care intervention: (a) If you were to grade your life before you brought your relative to the day center with 1 = low and 7 = high, what grade would you select? (b) If you were to grade your life after you brought your relative to the day center with 1 = low and 7 = high, what grade would you select? (c) Name three ways that the day center has helped you cope with caring for your relative. The Respondent's Profile plus

three impact questions took an average of six minutes to complete.

The Memory and Behavior Problem Checklist (see Appendix E) was developed by Zarit (1982) to determine the frequency of current problems and how caregivers react to them. Zarit (1982) reports that as a research tool, this instrument has been found to have adequate reliability and validity. The Memory and Behavior Problem Checklist took an average of eight minutes to administer.

The Activities of Daily Living (ADL) Checklist (see Appendix E) measures the patient's ability to perform day-to-day tasks such as eating, dressing, shaving, bathing, taking medication, and other activities. It was used to estimate the overall severity of the patient's deficits.

Zarit, Reever and Bach-Peterson, (1980) developed the Burden Interview (see Appendix E) to evaluate the subjective impact of caregiving. It was used to estimate the amount of stress that the caregiver was experiencing at that time. It is also effective in pretest-posttest situations. A converted score of 61-88 is an estimate of severe burden. The Burden Interview took about eight minutes to administer.

Zung (1972) developed the Depression Status Inventory (DSI) (Appendix E) to estimate the emotional state of individuals. It is a 20 question screening tool which addresses common characteristics of depression. The

questions address physical and emotional concerns such as appetite, sleep, activity, mental status, and coping abilities. A score of 61 or above is suggestive of a depressive disorder. The DSI took an average of eight minutes to administer.

After each interview, the RA scored the Burden Interview and the Depression Status Inventory (DSI). She had been instructed to alert the researcher if any score on the DSI was 61 or above. The researcher was prepared to offer referral services as indicated. Table 1 shows that all respondents scored less than 61 on both tests.

A master code sheet was kept in a locked file cabinet in the researcher's office. Each respondent's name and corresponding code number, i.e., 001 to 100, were entered on the master code sheet. The RA wrote the assigned code number and length of time it took to administer the particular tool on each interview set.

Data Analysis

Data analysis focused on examination of female caregivers' demographics, ratings of perceived coping skills before and after day center intervention, and responses on the Zung Depression Status Inventory. The data were analyzed using frequencies, means, standard deviations, and student t-tests. In addition, histograms were used to illustrate differences in before and after ratings of

perceived coping skills as well as the variation in responses on the Zung Depression Status Inventory. The next section presents a detailed analysis and interpretation of the data. Descriptive statistics were used to analyze data.

Chapter 4

ANALYSIS AND INTERPRETATION OF DATA

This section provides an analysis and interpretation of the data used in this study. The following data were examined (a) female caregivers demographics, (b) ratings of perceived coping abilities before and after intervention, and (c) scores on the Zung Depression Status Inventory. The study is a secondary analysis of data collected for a previous study (Lewis, 1987). The objective of this study was to investigate the following research questions:

1. Will female caregivers report increased coping abilities for caring for an elderly relative with dementia after day center intervention?
2. How will female caregivers using a day center intervention score on the Zung Depression Status Inventory (DSI) scale?

A more explicit look at these two general research questions was accomplished via the following hypothesis:

1. Through participation in day center intervention, female caregivers will increase their coping skills.
2. Female caregivers using a day center intervention will achieve scores below 61 on the Zung Depression Status Inventory Scale.

Forty-one respondents participated in Lewis' (1987) study. Thirty-six (87%) of the 41 respondents were female. This reflects the composition (76%-86%) of female caregivers in the general population and related studies (Gallagher et al., 1989; Green & Monahan, 1989; Montgomery & Borgatta, 1989; Toseland & Rossiter, 1989).

Twenty-five of the 36 female respondents completed all items on the data collection instruments. The present study is limited to data from the completed instruments. Consequently, data from 25 female caregivers were analyzed in this study ($N=25$).

Demographic Data

As shown in Table 1 the ages of the female caregivers in this study ranged from 31 to 73. The mean age was 52.88 with a standard deviation (SD) of 11.99. The mean age reported for caregivers in this study was consistent with the mean ages reported in related studies. Gallagher et al. (1989) reported a mean age of 58.4 in a study of depression in family caregivers. In an analysis of group interventions as support for caregivers, Toseland and Rossiter (1989) reported a mean age of 51.4.

The level of education among the female caregivers ranged from 11 to 18 years. Table 1 indicates that eighty-six percent of the female caregivers in this study had completed 12 or more years of education ($M=13.07$). This is

comparable to the educational status of caregivers in similar studies. Lawton, Brody, and Saperstein (1989) and Quayhagen M.P. and Quayhagen, M. (1989) reported education means of 12.0 ($\bar{M}$ = 12.0) and 14.4 ($\bar{M}$ = 14.4) respectively. Sixteen (64%) of the respondents had completed from 1 to 6 years of education beyond high school (see Table 1).

Respondents were asked how many children they had living within 30 miles of their home. Table 1 shows that twenty-three (92%) respondents reported that they had one or more children living no further than 30 miles away. The review of literature failed to reveal similar data related to the proximity of children to caregivers. However, the gerontological literature (Brody, 1985; Brody, Hoffman, Kleban, & Schooner, 1989; Harowitz, 1985; Young & Kahana, 1989) suggests that there is a significant relationship between the level of stress and depression experienced by female caregivers and the quantity and quality of support provided by children and other family members. All of the respondents lived within a 30 mile radius of the day center.

A review of the respondent's employment profile indicates that 16 (64%) of the female caregivers were not employed. There is no indication as to what percentage of these caregivers quit working due to caregiver responsibilities, as this question was not asked. However, studies (Brody et al., 1987; Harowitz, 1982) indicate that

Table 1

Demographic Variables From Respondents' Profile

(N = 25)

 Age Range = 31 - 73 years (M = 52.88)

31 - 45	46 - 51	58 - 73
7 (28%)	9 (36%)	9 (36%)

 Education Range = 11 -18 years (M = 13.07)

Completed	Completed	Completed
<12 years	12 years	>12 years
1 (4%)	8 (32%)	16 (64%)

Children Within 30 Miles of Caregiver Home

Yes	No
23 (92%)	2 (8%)

Employment

Full Time	Part-time	Not at all
4 (16%)	5 (20%)	16 (64%)

as many as 28% of non-working caregivers have reported quitting their jobs because of their caregiving responsibilities. Scharlach and Boyd (1989) suggest that community based programs such as day care and respite care can support keeping caregivers in the workforce.

Analysis of Data Regarding Coping Skills

The following data analysis examines female caregivers' responses to Hypothesis #1 regarding their perceived coping abilities before and after day center intervention. All respondents were using the services of the same day center at the time of data collection.

Hypothesis #1: Through participation in a day center intervention female caregivers will increase their coping skills.

Data analysis for this research question focused on two of the three impact questions (see Appendix D). Female caregivers' perceptions of coping abilities were assessed using two measures. The first measure was their response to the question: "If you were to grade how your life was before you brought your relative to the day center with 1 = low and 7 = high, what grade would you select?" The second measure was their response to the question, "If you were to grade how your life was after you brought your relative to the day center, with 1 =low and 7 = high, what grade would you select? Responses to each of these questions were analyzed

using frequencies (See Figure 1) means, standard deviations and t-tests (see Table 2).

Figure 1 is a histogram of respondents' ratings of perceived coping skills before and after day center intervention. The histogram provides a graphic presentation of the frequency of responses for each measure. In addition, the histogram provides a visual comparison of the two measures. From the histogram it is possible to see the shape of the distribution, that is how much spread or variability there is among the ratings and where the ratings are concentrated.

As shown in Figure 1, the ratings of perceived coping skills before day center intervention were concentrated in the area of the lower values (1-4). Sixteen (64%) of the before ratings were in the 104 range. Seven (28%) of the ratings of perceived coping skills after day center intervention were at the lower range.

Figure 1 shows that eighteen (72%) of the ratings after day center intervention were concentrated in the area of the higher values (5-7). Seven (28%) of the after ratings were in the lower range (1-4).

Figure 1 indicates that the ratings for perceived coping skills before day center intervention were more variable (range = 1-7) than the ratings after day center intervention (range = 3-7). Table 2 provides additional

FIGURE 1 CAREGIVERS COPING PERCEPTIONS BEFORE AND AFTER
DAY CENTER INTERVENTION (N=25)

insight into the variability of the ratings between the two measures.

Table 2 presents the means, standard deviations and t-test for the respondents ratings of perceived coping skills before and after day center intervention. The means and standard deviations were examined to better understand the variability of the ratings. The t-test was used to determine if the means of the before and after ratings were far enough apart to indicate a significant difference.

Analysis of Table 2 data reveals a mean of 3.68 (SD 1.88) for ratings of perceived coping skills before day center intervention. The mean for ratings after day center intervention was 5.40 (SD 1.284).

The one-tailed test was used due to its sensitivity to greater differences in one direction. The histogram in Table 1 suggests a greater difference in the direction of higher ratings. As shown in Table 2, the comparison of the before and after ratings yielded a significant difference. The t-test results indicate that the female caregivers increased coping skills after day center intervention. The test was significant at the $< .01$ level.

Table 2

Comparison of Female Caregivers Perceived
Coping Skills Before and After
Day Center Intervention

(N = 25)

	<u>M</u>	SD	
Before	3.6800	1.887	
After	5.4000	1.384	
	<u>M</u>	SD	t
Difference	1.7200	1.621	5.31*

*P < .01

Hypothesis #2: Female caregivers using a day center intervention will achieve scores below 61 on the Zung Depression Status Inventory.

The Zung Depression Status Inventory (Zung, 1972) was used to test Hypothesis #2. The Zung Depression Status Inventory (DSI) is a 20 item questionnaire with a minimum score of 20 and a maximum score of 100. Respondents were asked to rate each item on a scale of 1-4. The numbers (1-4) corresponds to the level of severity of observed or reported depression: None = 1, Mild =2, Moderate = 3, and Severe = 4.

A plan was in place for referral of respondents receiving a score of 61 or above. The plan included additional testing and treatment as indicated. However, it was not necessary to activate this plan, all respondents received scores of less than 61 (see Figure 2).

Figure 2 presents a histogram of the frequency of scores on the Zung Depression Status Inventory. As shown on the histogram the highest score received by any respondent was 49 and the lowest score was 28 (range = 28-49). Further examination of Figure 2 reveals a concentration of scores (56%) near the center of the histogram. Only one (12%) respondent received a score of 49 and one (12%) received a score of 28. The majority of the scores were equally distributed on each side of the histogram.

FIGURE 2 CAREGIVERS SCORES ON THE ZUNG DEPRESSION STATUS INVENTORY
(N=25)

Provided in Table 2 is the percentage of respondents receiving each score. The frequencies presented in the histogram in Figure 2 and the percentages shown in Table 2 support Hypothesis #2: Female caregivers using a day center intervention will achieve scores below 61 on the Zung Depression Status Inventory.

Respondents were already using the services of the day center when they completed the Zung Depression Status Inventory. Consequently, there are no before scores for comparison. Unlike the questions in measure one, no tool was available for retrospective assessment of depression.

Chapter 5

CONCLUSIONS AND RECOMMENDATIONS

This study examined demographical characteristics, perceived coping skills, and depression status of female caregivers of elderly relatives with dementia. Data related to coping skills and depression status were generated via the exploration of two hypothesis. First, the effect of day center intervention as a means of increasing perceived coping skills was examined. Second, the level of depression experienced by female caregivers using day center intervention was assessed. This section provides conclusions and recommendations based on these data. Implications for the use of nursing actions in relation to the conceptual framework are an integral part of this section.

Conclusions

The demographic characteristics of participants in this study appear to be representative of the general population of female caregivers. However, the data related to proximity of children is worth noting. These data reveal that 23 (92%) of the female caregivers had at least one child living within a 30 mile radius of the caregivers home. The review of literature revealed that the proximity of children is a major issue among caregivers (Brody, 1985; Montgomery & Borgatta, 1989; Stone, Cafferata, & Sangl,

1987). These data provide information that has relevance to the planning and implementation of support programs for female caregivers of elderly relatives with dementia. The quality and quantity of support provided by children is significant in promoting self-care and reducing stress for the caregiver.

Implications for use of the conceptual framework included supportive-educative programs to maximize the quality and quantity of assistance provided by children. Another aspect of the program would be to enhance female caregivers' skills for coping with negative situations involving lack of assistance from children.

Analysis of data related to Hypothesis #1 supports the use of day center intervention as a means of increasing perceived coping skills of female caregivers of elderly relatives with dementia. Eighteen (72%) of the female caregivers reported increased coping skills after using the services of the day center. Six (24%) respondents indicated no change in perceived coping skills. Only one (4%) respondent reported a decrease in perceived coping skills after day center intervention.

Exploration of the reason for a decrease in perceived coping skills was not in the scope of this study. However, it is well known that various life events and situations have the potential of influencing perceived coping skills.

Factors that may contribute to a decline in coping skills include a decline in the physiological and psychological well being of the caregiver, the progressive nature of dementia in the care recipient, failure to utilize the full services of the center, recipient's resistance to use of center, and feelings of guilt related to relinquishing a portion of caregiving responsibilities.

Day center intervention provides an opportunity for the female caregiver to engage in self-care. The conceptual framework serves as a structure for influencing coping patterns through stress management, changing self-sacrificing behavior, health awareness, and the development of a proficiency in dealing with unavoidable situations.

The findings related to Hypothesis #2 are important, although not definitive. Data supports the hypothesis that female caregivers using day center intervention will achieve scores of less than 61 on the Zung Depression Status Inventory. All (100%) respondents achieved scores of less than 61 on the Zung Depression Status Inventory. However, due to a lack of pretest scores, there is no way of knowing if these data represent a change in the female caregivers depression status.

Although findings related to Hypothesis #2 are inconclusive, reports from several studies (Fitting, Rabins, Lucas, & Eastham, 1986; Gallagher et al., 1989; Harowitz,

1985; Stone, Cafferata, & Sangl, 1989) suggest that female caregivers of elderly relatives with dementia are at risk for depression. Gallagher et al. (1989) describes depression as a potentially disabling condition that is associated with problems in daily functions that tend to compromise caregivers' ability to maintain themselves adequately in their roles.

A number of potentially predisposing factors have been identified in relation to depression among female caregivers of elderly relatives with dementia (Harowitz, 1985; Stone, Cafferata & Sangl, 1989). These factors include inadequate coping skills, limited social support and stress.

These findings have implications for a the gerontological nurse specialist as educator in day center intervention. This conceptual framework provides a guide for teaching self-care skills for coping with stressful situations. Effective self-care skills help regulate reactions to stressors in order to reduce potential for depression. In addition, self-care as a means of prevention and health promotion can be addressed under this conceptual framework.

The conceptual framework for this study was a combination of Orem's self-care conceptual framework and Selye's stress management strategies. This conceptual framework provides a guide for teaching coping skills for

dealing with stressful situations in order to reduce potential for depression.

Orem's self-care conceptual framework (Orem, 1980, p. 96) recognizes three nursing systems: (a) wholly compensatory, (b) partly compensatory and (c) supportive educative (see Appendix A). The wholly compensatory system is for situations where the client is unable to engage in self-care actions that require self-directed and controlled ambulation and manipulative movement. Nursing action for clients with these limitations involves total care, maintaining a safe environment, and psychological support.

The partly compensatory system includes situations where both the nurse and client perform care measures or the actions involved in manipulative tasks or ambulation. Nursing actions include providing assistance, supervision, and teaching of self-care measures, psychological support, and maintaining a safe environment.

The supportive-educative system is for situations where the client is able to perform self-care measures but requires assistance in engaging in developmental self-care. Nursing actions include providing guidance, emotional support, and teaching. Teaching should include strategies for the development of decision-making abilities and coping skills.

The supportive-educative system addresses the primary needs of the female caregivers in this study. However, certain aspects of each system may be applicable to the needs of an individual female caregiver.

Selye's stress model is expressed in the General Adaptation Syndrome (GAS) (see Appendix A). The GAS includes three stages of response to stress: a) alarm reaction, b) stage of resistance, and c) exhaustion. The alarm reaction stage mobilizes the body's defense forces for fight or flight. In the stage of resistance coping mechanisms are intensified with an optimal adaptation to stress. The exhaustion stage occurs when bodily resources are depleted due to prolonged exposure to stress. Lack of effective intervention at this stage could result in death.

Nursing actions in the alarm reaction stage include teaching. The primary goal is the development providing assistance and guidelines in the identification stressors, and the maintenance of physiological and psychological well-being. Teaching strategies include relaxation techniques and the development of coping skills.

Nursing action in the stage of resistance include providing guidance in the recognition of symptoms of stress, treatment, and exploring respite possibilities. The teaching of effective stress management and coping skills at

this stage is essential in order to prevent progression to the stage of exhaustion.

The primary focus of nursing action for the exhaustion stage is treatment of symptoms and supportive care. The goal is the restoration of physiological and psychological stability.

In conclusion, findings in this study suggest that day center intervention has the potential for increasing coping skills of female caregivers of elderly relatives with dementia. The day center decreases the amount of time required for caregiving and increases time for self-care. The conceptual framework provides a structure for teaching self-care measures which could have the effect of reducing stress and decreasing the potential for depression.

Recommendations

The literature review and findings in this study provide multiple implications for the use of day center intervention for female caregivers of elderly relatives with dementia. Several recommendations in the areas of research, clinical practice and legislation were derived from these implications. The first recommendation is to redesign the study using an experimental design instead of the ex post facto descriptive design. An experimental design allows the researcher to employ random assignment, use a control group, and manipulate the independent variable. The researcher

should limit the study to primary data analysis in order to increase control over design and sample size. In addition, the use of primary data provides an opportunity for incorporation of the conceptual framework and information from the literature to selection of assessment tools.

Two aspects of data collection should be included in the revision process. First, the demographic section should be expanded to include additional information regarding characteristics and needs of the female caregiver. Second, alternative data collection methods should be explored with a focus on improvement of accuracy in reporting.

The demographics section should be expanded to include the quality and quantity of support received from children, relatives, friends, and others. The quality and quantity of support provided by family, friends, and others is significant in helping caregivers meet self-care needs. In addition, the demographics section should include physiological, psychological, and sociocultural information about the caregiver, as well as the care recipient. Perceptions of coping skills are greatly influenced by these factors. Furthermore, the employment information should state whether the caregiver's employment status has been effected by caregiving responsibilities.

The data collection method was limited to a one time, 30 minute, face-to-face, on site interview. All methods of data collection that involve verbal reports share a problem with accuracy. There is often no way to know whether what is reported is indeed true (LoBiodo-Wood & Haber, 1986). For example, although respondents were informed that their responses were confidential and would not affect their utilization of the day center, some may have declined out of fear of repercussions from the staff. However, this may not have been a relevant concern because the researcher and research assistant were not members of the day center staff. In addition, individual responses were not made available to the day center staff.

An alternative to the face-to-face interview would be to ask the respondents to complete the questionnaire at home and mail them to the office of the researchers. However, this researcher has experienced a lower rate of completion and return of questionnaires with this method. Another alternative would be to conduct the interview in the respondent's home. The statement of confidentiality (See Appendix D) should be read to the respondent by the researcher. The respondent should be encouraged to ask questions regarding confidentiality.

The two impact items should be administered at three intervals. In addition, caregiver's progress should be

measured after a designated interval between the pre-test and the posttest.

Further research is recommended to examine the effects of ethnicity on perceived coping skills, stress, and depression. The review of literature revealed a dearth of information related to this subject area. However, it is well known that many ethnic groups including African Americans, Asians, and Hispanics often choose to care for their frail elderly family members in the home.

The second category of recommendations, clinical practice, is based on a continuum of care. Day center programs should provide for a continuum of care that is cognizant of the female caregivers prior self-care abilities, current self-care needs, and strategies required to maximize self-care capabilities.

Improved self-care skills may increase or decrease the caregivers potential to institutionalize the care recipient. The commonly expected outcome is improved coping abilities for caring for the care recipient in the home. However, in some instances, improved self-care skill may enable the caregiver to relinquish the primary caregiver role and consider extended respite and eventually long-term institutionalization for the care recipient. The gerontological nurse specialist should provide guidance and support for caregivers faced with this dilemma.

The continuum should also provide for home care. Day centers are not necessarily the intervention of choice for all caregivers. For example, a care recipient who is resistive to day center intervention may contribute to additional stress and depression for the caregiver. Home visits by the gerontological nurse specialist may be the intervention of choice.

Intervention should focus on increasing coping skills as a means of decreasing stress and reducing the potential for depression. The continuum should provide for intermittent extended respite such as two weeks respite in an inpatient program. Finally, when day center intervention is no longer an alternative to institutionalization, the day center program can be used as a means of easing transition. The gerontological nurse specialist can utilize the conceptual framework to reduce stress and ease the female caregiver's feelings of guilt in relation to the institutionalization of the care recipient.

The third category of recommendation is related to legislation. The primary focus is to determine how the information on caregivers can be utilized to influence legislators to present legislation that addresses the needs of an increasing population of caregivers and care recipients. Insurance coverage is a major issue affecting caregivers as well as care recipients. Health care should

be expanded to include preventive care, pay for care provided by relatives, and home based case management provided by gerontological clinical nurse specialist.

Funding should include day respite, periodic two-week respite and long-term care. Reimbursement at the various levels of care should be flexible and responsive to the needs of the caregiver as well as the care recipient.

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APPENDIX A
Conceptual Framework Models

Orem's Nursing Systems and Nursing Actions

Systems	Problem	Nursing Action
Wholly Compensatory	Unable to engage in self-care actions due to physiological and/or psychological limitations	Provide total care Provide psychological support Maintain safe environment
Partly Compensatory	Requires assistance with manipulative tasks and/or ambulation due to physiological and/or psychological limitations	Provide assistance and supervision Provide psychological support Teach self-care measures Maintain safe environment
Supportive Educative	Requires assistance related to decision making, behavior control and acquiring knowledge and skills	Provide guidance, support and teaching Provide psychological support Provide a developmental environment

Selye's General Adaptation Syndrome

Stage	Body's Reaction	Nursing Actions
Stage 1 Alarm Reaction	<p>Mobilization of the body's defense mechanisms</p> <p>Increase in hormone levels</p> <p>Enlargement of adrenal cortex</p> <p>Enlargement of lymph glands</p> <p>Weight loss</p>	<p>Provide assistance in identification of stressors</p> <p>Provide guidance in preventing stressors from becoming disruptive to physiological and psychological well-being</p> <p>Teach strategies for stress management and development of coping skills</p>
Stage 2 Stage of Resistance	<p>Optimal adaptation to stress</p> <p>Lymph glands return to normal</p> <p>Reduction in size of adrenal cortex</p> <p>Weight returns to normal</p>	<p>Provide guidance in symptoms of stress</p> <p>Recognition of symptoms of stress</p> <p>Treatment of symptoms</p> <p>Provide for respite</p> <p>Teach strategies for stress management and coping with stress</p>
Stage 3 Exhaustion and Disintegration	<p>Bodily resources are depleted</p> <p>Body loses its ability to resist stress</p> <p>Enlargement of adrenal glands</p> <p>Abnormal hormonal levels</p> <p>Weight loss</p>	<p>Treatment of symptoms</p> <p>Supportive care</p> <p>Prevent further decompensation</p> <p>Assist in regaining physiological and psychological stability</p>

APPENDIX B
Permission to Access Data

School of Applied Arts and Sciences • Department of Nursing • Graduate Program
One Washington Square • San Jose, California 95192-0057 • 408/924-3134

June 2, 1989

To: Dr. Serena Stanford
Office of Graduate Studies and Research

From: Irene D. Lewis, D.N.Sc.
Department of Nursing

Dear Dr. Stanford;

I am delighted that Mrs. Betty Baldwin, a graduate student enrolled in San Jose State University's Department of Nursing has requested to use data from a study I conducted in 1987. She has my permission to access that data. Since I am serving as her thesis advisor, I can also supervise her work. The data has no individual identifying marks. It has been reported in aggregate form using numerical codes.

If you need further information, please contact me at 4-3160.

Sincerely,

Irene D. Lewis, D.N.Sc., FAAN,
Associate Professor,
Department of Nursing

APPENDIX C
Approval to Conduct Study

Office of the Academic Vice President • Associate Academic Vice President • Graduate Studies and Research
One Washington Square • San Jose, California 95192-0025 • 408/924-2480

To: Betty Sanders Baldwin, Nursing

**From: Charles R. Bolz
Office of Graduate Studies and Research**

Date: January 22, 1990

The Human Subjects Institutional Review Board has approved your request to use human subjects in the study entitled:

**"Female Caregivers of Relatives with Dementia:
Implications for Daycare Center Intervention"**

This approval is contingent upon the subjects participating in your research project being appropriately protected from risk. This includes the protection of the anonymity of the subjects' identity when they participate in your research project, and with regard to any and all data that may be collected from the subjects. The Board's approval includes continued monitoring of your research by the Board to assure that the subjects are being adequately and properly protected from such risks. If at any time a subject becomes injured or complains of injury, you must notify Dr. Serena Stanford immediately. Injury includes but is not limited to bodily harm, psychological trauma and release of potentially damaging personal information.

Please also be advised that each subject needs to be fully informed and aware that their participation in your research project is voluntary, and that he or she may withdraw from the project at any time. Further, a subject's participation, refusal to participate or withdrawal will not affect any services the subject is receiving or will receive at the institution in which the research is being conducted.

If you have any questions, please contact Dr. Stanford or me at 4-2480.

✓ **cc: Irene Lewis, Ph.D.**

APPENDIX D
Informed Consent

INFORMED CONSENT

You are invited to participate in a study to examine aspects of the natural history of memory loss in the elderly. Specifically you are being asked to identify ways a day center has influenced how you cope with caring for a relative with memory loss. This study will also look at how/when you first noticed "something was wrong" with your relative; what you were told about your relative's problem at the time a diagnosis was offered.

Dr. I. Lewis, a professor at San Jose State University in the Department of Nursing is conducting this investigation. Her assistant is Ms. L. Martin, an undergraduate nursing student at San Jose State University. Ms. Martin will describe the study and answer your questions, if you have any. She will interview you, using a guided, structured interview format. It should take about thirty minutes of your time.

Information obtained from the study will be reported in groups. At no time will your individual responses be identified. There is no monetary compensation for your participation. Your decision whether or not to participate will not prejudice your future relations with the Day Center. If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without prejudice.

If you have any questions, please ask. If you have any questions later, Dr. I. Lewis and Ms. L. Martin may be contacted at (408) 277-2692, they will be happy to answer them. You will be given a copy of this form to keep (Optional).

YOU ARE MAKING A DECISION WHETHER OR NOT TO PARTICIPATE.
YOUR SIGNATURE INDICATES THAT YOU HAVE DECIDED TO
PARTICIPATE HAVING READ THE INFORMATION PROVIDED ABOVE.

SIGNATURE OF PARTICIPANT

DATE

APPENDIX E
Data Collection Forms

RESPONDENT'S PROFILE

CODE # _____

TIME _____

1. Sex Female _____ Male _____
2. Age _____
3. Type of relationship between patient and caregiver. On a scale of one to seven with one as low and seven as high, indicate the type of relationship you have

Circle only one number 1 2 3 4 5 6 7

4. The demented older person lives with you, caregiver _____
 The demented older person lives in a residential home _____
 The demented older person lives with someone else _____

(Select only one of the above choices)

5. How did you learn about the Day Center?
 Who referred you?

6. Ethnicity (Optional) _____

7. Education circle highest grade completed 1 2 3 4 5 6 7 8 9 10 11
 12 13 14 15 16 17

8. Are you employed? Yes _____ No _____
 Part-time _____ Number of years to date _____
 Full-time _____ Number of years to date _____

9. Do you live within 30 miles of the Day Center Yes _____ No _____
10. Do you have children? Yes _____ No _____ How many live within 20-30 miles of your home? _____
11. Do you take medications for your "nerves"? Yes _____ No _____
12. What is your religious preference? Protestant _____
 Catholic _____ Jewish _____ None or other _____
13. How did you first become aware something was wrong with your relative?

14. What was the main symptom that first caused you, your relative with memory loss or someone else to look for help?

15. Once your relative was diagnosed as having memory loss, what was your family told about the disease?
16. If you were to grade how your life was before you brought your relative to the day center with 1 = low and 7 = high, what grade would you select?
17. If you were to grade how your life was after you brought your relative to the day center with 1 = low and 7 = high, what grade would you select?
18. Name three ways that the day center has helped you cope with caring for your relative.

MEMORY AND BEHAVIOR PROBLEMS CHECKLIST**INSTRUCTIONS TO CAREGIVER:**

I am going to read you a list of common problems. Tell me if any of these problems have occurred during this past week. If so, how often have they occurred? If not, has this problem ever occurred? Here, take this card. Typed on it are the choices you are to use when you answer each questions. First, answer by giving the number according to how frequently the behavior happens or does not happens. Second, answer by giving the number according to how much this behavior bothers or upsets you when it happens. Now, any questions? Let us begin.

Code # _____
Time _____

MEMORY AND BEHAVIOR PROBLEMS CHECKLIST

INSTRUCTIONS TO INTERVIEWER: You want to describe as accurately as possible how often problems occur.

INSTRUCTIONS TO CAREGIVER:

"I am going to read you a list of common problems. Tell me if any of these problems have occurred during the past week. If so, how often have they occurred? If not, has this problem ever occurred?" Hand the subject the card on which the frequency ratings are printed.

FREQUENCY RATINGS

- 0 = never occurred
- 1 = has occurred infrequently (and not in past week)
- 2 = has occurred 1 or 2 times in past week
- 3 = has occurred 3 to 6 times in past week
- 4 = occurs daily or more often
- 5 = occurred frequently in past, but no longer occurs
- 7 = would occur, if not supervised by caregiver (e.g., wandering except door is locked)

REACTION RATINGS: How much does this bother or upset you when it happens?

- 0 = not at all
- 1 = a little
- 2 = moderately
- 3 = very much
- 4 = extremely

BEHAVIORS	FREQUENCY	REACTION
1. Asking the same questions over and over again	0 1 2 3 4 5	0 1 2 3 4
2. Trouble remembering recent events (e.g., items in the newspaper, on TV)	0 1 2 3 4 5	0 1 2 3 4
3. Trouble remembering significant events from the past	0 1 2 3 4 5	0 1 2 3 4
4. Loaning or misplacing things	0 1 2 3 4 5	0 1 2 3 4

5.	Wandering or getting lost	0 1 2 3 4 5 7	0 1 2 3 4
6.	Unable to find way about indoors	0 1 2 3 4 5	0 1 2 3 4
7.	Unable to find way about familiar streets	0 1 2 3 4 5	0 1 2 3 4
8.	Not recognizing a familiar place	0 1 2 3 4 5	0 1 2 3 4
9.	Not recognizing familiar people	0 1 2 3 4 5	0 1 2 3 4
10.	Not recognizing a familiar object	0 1 2 3 4 5	0 1 2 3 4
11.	Forgetting what day it is	0 1 2 3 4 5	0 1 2 3 4
12.	Starting, but not finishing things	0 1 2 3 4 5	0 1 2 3 4
13.	Difficulty concentrating on a task	0 1 2 3 4 5	0 1 2 3 4
14.	Hiding things (money, jewelry, etc.)	0 1 2 3 4 5	0 1 2 3 4
15.	Being suspicious or accusative	0 1 2 3 4 5	0 1 2 3 4
16.	Destroying property	0 1 2 3 4 5	0 1 2 3 4
17.	Doing things that embarrass you	0 1 2 3 4 5	0 1 2 3 4
18.	Waking you up at night	0 1 2 3 4 5	0 1 2 3 4
19.	Being constantly restless	0 1 2 3 4 5	0 1 2 3 4
20.	Spending long period of time inactive	0 1 2 3 4 5	0 1 2 3 4
21.	Being constantly talkative	0 1 2 3 4 5	0 1 2 3 4
22.	Talking little or not at all	0 1 2 3 4 5	0 1 2 3 4
23.	Appears sad or depressed	0 1 2 3 4 5	0 1 2 3 4
24.	Appears anxious or worried	0 1 2 3 4 5	0 1 2 3 4
25.	Engaging in behavior that is potentially dangerous to others or self	0 1 2 3 4 5	0 1 2 3 4
26.	Dwelling on the past	0 1 2 3 4 5	0 1 2 3 4
27.	Reliving situations from the past	0 1 2 3 4 5	0 1 2 3 4
28.	Seeing or hearing things that are not there (hallucinations or illusions)	0 1 2 3 4 5	0 1 2 3 4
29.	Eating sweets excessively	0 1 2 3 4 5	0 1 2 3 4
30.	Not eating at all	0 1 2 3 4 5	0 1 2 3 4
31.	Any other problems (specify)	0 1 2 3 4 5	0 1 2 3 4

ACTIVITIES OF DAILY LIVING

INSTRUCTIONS TO CAREGIVER:

I am going to read you a list of common activities. Tell me to what degree your relative can perform each activity by responding with a number from a card that I will give you shortly. Then tell me your reaction to that performance level by responding with a number from that same card. Here is the card. Take it. Typed on it are the choices you can select by number...answer with the number only. Questions? Now, let us begin.

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