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Dependent elder care : the impact on caregiver burden

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DEPENDENT ELDER CARE:
THE IMPACT ON CAREGIVER BURDEN

A Thesis
Presented to
The Faculty of the School of Nursing
San Jose State University

In Partial Fulfillment
of the Requirements for the Degree
Master of Science

By
Laura M. Bour
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ABSTRACT

DEPENDENT ELDER CARE: THE IMPACT ON CAREGIVER BURDEN

by Laura M. Bour

The purpose of this descriptive, correlational study was to determine if impairment of a dependent elderly person's ability to perform activities of daily living was related to the level of perceived burden in the caregiver. Forty caregivers from a hospital respite center and a senior day center participated. Data were collected using the Zarit Burden Interview, the Index of Independence in ADL, and a demographic questionnaire. Orem's self-care model was the conceptual framework for this study.

Although caregivers reported moderate burden and care receivers were low functioning, there was not a statistically significant correlation between the ADL ability level of a dependent elder and perceived caregiver burden. Caregivers reported distress from negative behaviors of care receivers such as resisting care, wandering, and keeping family awake at night. Research is necessary to understand caregiver needs. Recognition of caregiver needs will enable nurses to provide support and education to meet those needs.

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Chapter 1

INTRODUCTION

Montgomery (1993) reported an individual provides greater and greater amounts of assistance to a dependent family elder before reaching the stage of defining one's self as a caregiver. At this stage, a spousal caregiver is already performing personal care tasks for his/her spouse, whereas a nonspousal caregiver will very soon need to provide one or more personal care tasks for the elderly family member. The personal care tasks of bathing, feeding, transferring, toileting, and dressing, are commonly called activities of daily living (ADL).

As the elderly person ages and becomes increasingly frail, the burdensome demands of caregiving multiply. Meanwhile, the caregiver also ages and develops, or is at risk for developing, chronic health problems (Brody, 1981). The provision of informal care to a chronically ill, elder family member can be physically, emotionally, socially, and financially overwhelming (George & Gwyther, 1986). Caregiving may continue for years, with the possible consequence of increasing stress for the caregiver (Osterkamp, 1988).

Advances in medical technology have been responsible for the population of our society living longer. Due to the decline in our country's birth rate, there has been a decrease in the number of adult children available to care for aging parents. Demographic data indicate that 12% of the population of the United States will be over the age of 65 by the year 2000, and this percentage will continue to increase in future years. The fastest growing group of elderly persons are the frail elderly, those over 85 years of age (Osterkamp, 1988). Of the persons who are over 65 years old, 86% have one or more chronic conditions which affects physical and/or mental functioning. Ninety-five percent of aged individuals are community residents, the remaining 5% reside in institutions (Cox, 1993; Steffl, 1984).

The rapid demographic changes in the United States have made family caregiving an important social issue (Parks & Pilisuk, 1991). Demographic trends predict more elderly persons and fewer family caregivers. Caregiving has historically been considered a family affair (Lerner, Somers, Reid, Chiriboga, & Tierney, 1991). The majority of families prefer to keep their elderly family member in the home for as long as possible, preserving the elderly person's dignity and independence (Melchor, 1988). As early as 1985, Brody reported that caring for a dependent elderly parent had become a normative experience. Public policy supports and depends on family caregiving as a cost effective way of saving scarce resources (Hogan, 1990; Linsk, Keigher, & Osterbusch, 1988). However, Stone, Cafferata, and Sangl (1987) question whether informal caregivers have the capacity to continue providing the bulk of home based caregiving duties in our aging society.

The majority of elderly persons prefer to live out their lives in their own homes. As people age, they wish to remain their own self-care agents and fear becoming dependent on others

(DeBettignies, Mahurin, & Pirozzolo, 1990). They wish to be functionally independent, to be self-reliant, and to maintain personal self-control. Living independently within the community is a way to maintain the personal self-concept, the feeling of self-worth (Smits & Kee, 1992).

The elder population, those persons over 65 years of age, have the greatest proportion of chronic illness. Longer life expectancy means periods of disability and increasing care concerns (Lubkin, 1986, p. 10). A supportive family can help an elderly person maintain independence and prevent institutionalization (Brody, 1981; McFall & Miller, 1992). It is not unusual for three or more generations, not necessarily living in the same house, to be working together, aiding and assisting all family members (Chenitz, Stone, & Salisbury, 1991, p. 7). A congressional study found shared households became more common as the health of the older family member deteriorated (Subcommittee on Human Services of the Select Committee on Aging, 1987, p. 21).

According to health survey data, the majority of elderly persons remain active as they age (Burnside, 1988, p. 384). Affluent elderly persons have more options to provide self-care in the home other than poor elderly persons. The aged poor, who cannot afford the fees for health care services, may have no other alternative than to reside in the community receiving assistance only from kin (Padula, 1992). Another elderly group, those with deteriorating activities of daily living skills and lacking family or friends to contribute assistance, have been found to be overrepresented in mental hospitals (Loebel & Eisdorfer, 1984, p. 48).

The elderly are commonly plagued with one or more chronic illnesses rather than an acute illness. Once a chronic condition is present, life-long problems can be expected. Chronic illness often acts in a cyclic manner, affecting the social, psychological, physical, and economic aspects of the elder's life. The individual must try to live a normal life while attempting to deal with the symptoms and any functional disability or health crisis connected with the chronic condition. Families tend to believe that managing an elder's chronic health problem is mainly a home-care responsibility. Formal health care living arrangements, such as a nursing home, are used only when the family no longer can provide for the needs of the chronically ill family member (Lubkin, 1986).

As the elder population has increased, the number of people informally caring for them has also grown. Caregiving is most often provided by a family member (Caserta, Lund, Wright, & Redburn, 1987). Informal primary caregivers are most often women, the spouse, daughter, or daughter-in-law of the elder (Brody, 1981). Male spouses make up only 13% of primary caregivers (Browning & Schwirian, 1994).

According to a government study, the average woman spends 17 years as the dependent-care agent for a child and 18 years as the dependent-care agent for a family elder (Subcommittee on Human Services of the Select Committee on Aging, 1987, p. 9). Providing the self-care requisites for a healthy child has a different emotional consequence than providing the self-care requisites for a dependent elder. The child has a future full of hope and unknown potential. On the other hand, the dependent elder can be expected to deteriorate physically and is approaching the end of life. Furthermore, the decline in the mental, physical, and social abilities of the dependent elderly family member can be a symbolic reminder of the destiny of the caregiver (Pilisuk & Parks, 1988; Sommers, 1985).

Typically, in the case of spouses, the caregiving role falls to the wife as she is usually younger, in better health, and has less self-care deficits than her husband. Elderly couples, with one acting as the caregiver of the other, may lead isolated lives. Both elders are generally affected with multiple medical problems and functional impairments. The heavy responsibilities of giving care can be exhausting and curtail other activities (Berman, Delaney, Gallagher, Atkins, & Graeber, 1987). Another predicament faced by aging couples is that of the change in male and female roles. Couples who had firmly maintained strict role tasks may have to adapt to a division of labor according to who can best do the job (Arthritis Foundation, 1987).

Statement of the Problem

Social policy trends have placed an increasing emphasis on family caregiving. Home based caregiving by a family member maintains the family as a unit and is cost effective for the government (Hogan, 1990; Melcher, 1988; Stone, 1991).

Deimling and Bass (1986) found caregiver burden was directly associated with the elderly dependent person's level of physical limitations. An incapacity in two or more activities of daily living (bathing, feeding, transferring, ability to toilet self, and dressing) is required for access into most state and community based care programs (Stone & Murtaugh, 1990). Incontinence is not included among the list of ADL deficits for eligibility, as it is considered an impairment, not a disability. These requirements severely restrict the number of elderly persons who are eligible for home health care, leaving many caregivers without assistance.

Family members are the primary caregivers of elderly persons not living within an institution. Investigators have reported that health problems, which limit the ability to perform caregiving tasks, are found in 30% of caregivers of the frail elderly (Christianson & Stephens, 1986, p. 44). The amount of care provided to the recipient depends on the disability level of the elder. It is rare for family caregivers to ask for outside assistance until the responsibility of elder care becomes too difficult (Stone et al., 1987). Despite problems associated with caregiving, most families accept the challenge of dependent care agency and care for their elder family member at home.

The caregiver who has 24 hour responsibility for a chronically ill elder may have unmet needs. The provision of informal, home-based care to an elderly family member is often done at great emotional cost to the caregiver (Chenowith & Spencer, 1986). The work is time-consuming, unpaid, and unrecognized (Green, 1991; Stone et al., 1987). Horowitz (1985) reported the consequences of caregiving activities to be emotional strain and lack of time for personal activities. Research by Bergman-Evans (1994b) and Brody (1985) found depression to be one of the feelings experienced by caregivers. Caregiving burden can be so stressful that in extreme cases the caregiver can become abusive toward the dependent elder (Fulmer, 1991; Paveza et al., 1992; Sanders & Morley, 1993). Miller and Montgomery (1990) found it is common for a middle aged caregiver to be unable to adequately carry out work and family roles due to the burden of caregiving. Additional information about the possible risks of caregiving will be provided in the literature review.

These findings suggest that factors causing caregiver burden should be identified in order to develop and provide therapeutic interventions which would assist the caregiver to cope with the problems of caregiving. One of the factors related to caregiver burden may be deficits in activities of daily living in the dependent elder person.

Research Question

This study addressed the following research question:

Is there a relationship between the level of deficit in activities of daily living of a dependent family elder to perceived caregiver burden?

Hypotheses

This study tested the following hypotheses:

1. A caregiver who provides a high level of activities of daily living care for a dependent elder as indicated on the Index of Independence in Activities of Daily Living (Katz, Downs, Cash, & Grotz, 1970) will report higher scores of perceived feelings of burden on the Zarit Burden Interview (Zarit, Orr, & Zarit, 1985; Zarit, Reever, & Bach-Peterson, 1980).
2. A caregiver who provides a low level of activities of daily living care for a dependent elder as indicated on the Index of Independence in Activities of Daily Living (Katz et al., 1970) will report lower scores of perceived feelings of burden on the Zarit Burden Interview (Zarit et al., 1985; Zarit et al., 1980)

Purpose and Need

The purpose of this study was to determine if impairment of a dependent elder's ability to perform activities of daily living was related to the level of perceived burden in the caregiver. The activities of daily living (ADL) are eating, bathing, toileting, transferring, and dressing. These are actions people carry out as their own self-care agents habitually and universally. Performance of ADLs without assistance is necessary for functional independence (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963).

Few studies have been performed to explore if ADL status interrelates with caregiver burden and results of the studies have been equivocal (Pearson, Verma, & Nellett, 1988). One investigation by Zarit et al. (1980) did not find limitations in ADLs to be related to caregiver burden, whereas studies by Farran, Keane-Haggarty, Tatarowitz, and Scorza (1993) and Pearson et al. (1988) found a positive interrelationship.

The caregiving role can be insidious in nature, with the dependent-care agent at first only providing a brief amount of attention to the aging family member. The provision of self-care requisites for a few minutes a day gradually increases as the physical and/or mental powers of the elder diminishes. Research to explore if the self-care agency in ADL ability of an elder influences the level of perceived caregiver burden has been minimal. The assumption has been that caregiver burden can be predicted as the elder's functional ADL dependence on the caregiver increases (Zarit, Todd, & Zarit, 1986). This study was a test of that assumption to explore if a relationship exists.

Definition of Terms

The following are definitions of key terms used in this study:

1. Activities of daily living (ADL) are bathing, dressing, toileting, eating, and transferring. All are self-care actions usually performed in the course of a normal day by adults. In this study, ability level in ADLs of the dependent elder is measured by the Index of Independence in Activities of Daily Living. Performance without assistance is necessary for functional independence (Katz et al., 1963).

2. Agent is "the person taking action" (Orem, 1985, p. 84).

3. Caregiver is the provider of one or more personal care tasks for an elder. The tasks, known as activities of daily living, are

bathing, toileting dressing, transferring, and eating (Montgomery & Koslowski, 1994).

4. Caregiver burden is "the extent to which caregivers perceived their emotional or physical health, social life, and financial status as suffering as a result of caring for their relative" (Zarit et al., 1986). In this study, caregiver burden is measured by the Zarit Burden Interview (Zarit et al., 1985; Zarit et al., 1980).

5. Chronic illness is "the irreversible presence, accumulation, or latency of disease states or impairments that involve the total human environment for supportive care and self-care, maintenance of function, and prevention of further disability" (Lubkin, 1986, p. 6).

6. Dependent is the condition of being reliant upon someone for help or support (Urdang & Swallow, 1983, p. 315).

7. Dependent care agent is "the provider of infant care, child care, or dependent adult care" (Orem, 1985, p. 84).

8. Elder is a person 65 years of age or older, exhibiting varying degrees of health and functioning.

9. Family caregivers are family members who provide unpaid, nonprofessional care to a family member. Family caregivers are most often women, the spouse, daughter, or daughter-in-law of the elderly person (Brody, 1981).

10. Independent elderly are persons, 65 years of age and older, who live in their own home, who can perform their own self-care, and can leave their home whenever they wish (Stokes & Gordon, 1988).

11. Primary caregiver is the person providing the greatest amount of day-to-day physical and supportive care for a dependent elder (Stone et al., 1987).

12. Self-care is "the productions of actions directed to self or to the environment in order to regulate one's functioning in the interests of one's life, integrated functioning, and well being" (Orem, 1985, p. 31).

13. Self-care agent is "the provider of self care" (Orem, 1985, p. 84).

14. Self-care agency is "the complex capability for action that is activated in the performance of the actions or operations of self-care" (Orem, 1985, p. 31).

15. Self-care deficit is "a relationship between self-care agency and therapeutic self-care demand in which self-care agency is not adequate to meet the known therapeutic self-care demand" (Orem, 1985, p. 31).

16. Self-care requisites are "the purposes to be attained through the kinds of actions termed self-care. Three types of self-care requisites are identified: universal, developmental, and health-deviation." (Orem, 1985, pp. 85-86).

Research Design

A non-experimental design was used in this study to gain information about the relationship of perceived caregiver burden and the ADL ability of the dependent elder. The study was also descriptive correlational in nature. No interventions were introduced to control or manipulate the participants. The goal of descriptive correlational research is to describe the relationship among variables rather than infer cause-effect relationships (Polit & Hungler, 1985, p. 114). In this study, the dependent variable was perceived caregiver burden and the independent variable was the ADL ability of the dependent elder.

Data were collected using the Zarit Burden Interview (see Appendix A), the Index of Independence in Activities of Daily Living (see Appendix B), and a demographic questionnaire (see Appendix C). The population targeted were caregivers of dependent elders. The three questionnaires and a consent form were mailed to caregivers who, when interviewed by phone, said they were the primary caregiver of an elderly person and agreed to take part in the study.

Prior to initiating the investigation, approval was obtained from the Human Subjects Institutional Review Board of San Jose State University (see Appendix D). Two facilities, a senior day care center and a hospital dementia respite program, gave permission to have this study conducted at their sites (see Appendix E for senior day care center approval; see Appendix F for the hospital dementia respite program approval). In addition, the investigation at the hospital dementia respite program required approval from a panel on human subjects (see Appendix G).

Both organizations required specific information to be included in the consent form to be signed by the subjects from their facility.

Appendix H provides an example of the consent form used at the senior day care center, and Appendix I provides an example of the consent form used at the hospital dementia respite program.

Appendix J contains a copy of the notification from Dr. Katz giving permission to use the Index of Independence in Activities of Daily Living instrument (Katz et al., 1970). Appendix K contains a copy of the letter from Dr. Zarit providing permission to use The Zarit Burden Interview tool (Zarit et al., 1985; Zarit et al., 1980).

Scope and Limitations

The scope of this study is limited. It is a descriptive study of a caregiver population at one point in time. The results cannot be generalized beyond the study participants and the setting. Also, the study is limited by the sample population, the design and the method used for data collection.

The first limitation to be noted in this study is the choice of population. The population was limited to an accessible, voluntary, convenience group of caregivers of dependent elders from a community senior day care program and caregivers of dependent elders from a dementia respite program of a hospital. Both facilities are in the same metropolitan area. The dependent elderly persons were predominantly male, which does not reflect the aged persons in our society, in which the majority of elderly persons are females.

The study's second limitation was the design. The non-experimental framework does not eliminate the effects of extraneous variables. In addition, the non-experimental method cannot establish causal relationships (Abdellah & Levine, 1986, p. 171).

The third limitation is focused upon the method used to collect the data. The questionnaires given to the caregivers required data to be furnished to the researcher through caregiver self-report. The primary researcher was a staff nurse at the hospital site and known to the majority of the caregivers. The answers to the research questions may have been exaggerated by the caregivers in the hope that the data would facilitate placement of the elderly dependent person in long term care. On the other hand, the answers to the research questions could have been understated to indicate a low level of perceived caregiver burden. In the caregiver's judgement, de-emphasizing caregiver burden could have been perceived as the socially acceptable position to present.

Chapter 2

CONCEPTUAL FRAMEWORK AND REVIEW OF RELATED LITERATURE

This chapter contains the theoretical framework for the study and a general review of the literature. The literature review consists of two parts. The first part focuses on the consequences of caregiving burden. The second part presents information on perceived caregiver burden associated with the provision of activities of daily living (ADL) care to a dependent elderly person.

Conceptual Framework

Orem's self-care deficit theory of nursing (Orem, 1980, 1985) was selected as the theoretical basis for this study. The study explores if the level of an elderly person's ADL demands affects perceived caregiver burden. Perceptions of caregiving burden can impact self-care ability of the caregiver as well as the dependent-care ability of the caregiver. Orem (1985, p. 30) inferred that in dependent care situations, the well-being of a caregiver is linked with the health state and the level of care requirements of the dependent person.

Orem's self-care deficit theory of nursing is a general theory which focuses on the learned self-care ability of the individual to maintain the self and dependents in a state of wellness. The central idea of Orem's philosophy is the belief that man as a person has an innate ability to care for the self. Within the framework of the general theory are three related constructs: self-care or dependent-care, self-care deficit, and nursing systems.

The first construct of the theory is that of self-care or dependent care. Orem (1985, p. 84) states, "self-care is the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health, and well-being." Self-care is provided by a self-care agent; dependent-care is provided by a dependent-care agent. Orem uses the word "agent" to indicate the person performing the care activity.

The focal point of the self-care or dependent-care construct is the ability of the individual to be a self-care agent, and to interact with the environment while initiating independent self-care for the maintenance of the self or the dependent's health and life. Orem (1985, pp. 85-86) described three groupings of self-care requisites: universal, developmental, and health deviation.

The first grouping, universal self-care requisites, has eight basic requirements which are essential to promote and to preserve health in humans. These requisites are air, water, food, elimination, activity, rest and sleep, solitude and social interaction, protection from hazards, and a sense of normalcy. The second grouping, developmental self-care requisites, are related to developmental processes which are a part of the normal physical and emotional life cycle, such as pregnancy or death of a family member. The third grouping, health deviation, occurs if an individual becomes ill, becomes injured, has disabilities, or requires medical diagnosis or treatment. When unable to provide for self-care or dependent-care requisites, a self-care deficit exists and nursing agency is required.

Nursing agency is "the complex capability for action that is activated by nurses in their determination of needs for, design of, and production of nursing for persons with a range of types of self-care deficits" (Orem, 1985, p. 31). The self-care deficit construct, the second construct in Orem's theory (1980, 1985), requires the nurse to make a contract with the individual to provide nursing assistance to meet the needs that the individual is unable to meet independently. A nurse and client relationship begins in which the skills and specialized education of the nurse complements the skills and knowledge of the client to mutually provide a therapeutic level of care. Based on the level of self-care deficits, the third construct of Orem's theory, nursing systems, is activated.

A nursing system is "a continuing series of actions produced when nurses link one way of a number of ways of helping to their own actions or the actions of persons under care that are directed to meet these persons' therapeutic self-care demands or to regulate their self-care agency" (Orem, 1985, p. 31). A nursing system of care is prescribed to assist and support the individual to recover self-care capabilities.

Three basic variations in nursing systems are recognized: wholly compensatory nursing systems, partly compensatory nursing systems, and supportive-educative nursing systems (Orem, 1985, p. 152). Under the wholly compensatory nursing system, the client is unable to participate in any self-care task. Under the partly compensatory nursing system, the client is able to perform some, but not all, self-care tasks. In the supportive-educative nursing system, the client has the ability to be independent but needs some form of support such as teaching, guidance, provision of an environment focused on achieving health, or assistance in learning self-care measures.

Numerous research studies have reported that caregivers disregard their own physiological and psychological needs in fulfilling caregiving duties. Many of the studies are identified in the literature review which is contained in this chapter. Research literature also submits that caregivers may experience feelings of burden as a result of caregiving demands. Examples of these studies can also be found in the literature review. Orem (1980, 1985) emphasizes that self-care and dependent-care are learned activities. The framework for this research study utilizes the supportive-educative nursing system of care to improve the well-being of the caregiver.

The supportive-educative nursing system develops the caregiver's knowledge and skill to perform dependent-care actions. This system is the only one in which the requirements for help are confined to decision making, behavior control, and acquiring knowledge or skills (Orem, 1985, p. 156). Nursing agency can decrease stress and improve the quality of life for caregivers with perceived feelings of burden by placing the caregiver in a nursing system which will make an effort to relieve the impression of helplessness and burden and replace it with a feeling of competency.

Literature Review

Family caregiving involves many demands, challenges, and stressors. The needs of caregivers are often ignored as attention is focused on the needs of the dependent elderly person (Coleman, Piles, & Poggenpoel, 1994). Not all caregivers are stressed by caregiving, and some have described positive effects as the result of caring for the elderly family member (George & Gwyther, 1986; Kinny & Stephens, 1989; Lawton, Brody, & Saperstein, 1989; Seelbach, 1978).

This literature review is divided into two sections. The first part explores studies related to the possible consequences of perceived caregiver burden. In this section, the psychological, sociocultural, physiological, and developmental effects of caregiving are covered. The second part of the literature review presents studies which focus upon the perceived caregiver burden associated with providing ADL care for a dependent elderly person.

Possible Consequences of Caregiver Burden

Sommers and Shields (1987) found that 80% to 90% of elderly persons remain in the community and are cared for at home. Caregivers are most often females, and in some instances may have children as well as the dependent elder in need of care (Baum & Page, 1991). The terminology, 'sandwich generation', is the description of an adult caring for one or more young family members and at least one aged family member. This growing group of caregivers have had an effect on all segments of our society as they attempt to balance caregiving tasks and professional careers. (Eubanks, 1991; Stone & Short, 1990).

Numerous researchers have reported on the psychological and sociocultural aspects of caregiving. Parks and Pilisuk (1991) reported the psychological costs of caring for a parent were greater for women than for men. Focusing on the caregiver's coping style in a study of 125 female and 51 male caregivers, the researchers found the consequences of depression, guilt, anxiety, and resentment in relationship to caregiving was greater in women. It was also reported that neither gender had a coping style that removed the negative psychological aspects of caregiving. Lutzky and Knight (1994) also found female caregivers to report more distress than did male caregivers. These results were attributed to gender differences in coping styles. Schott-Baer (1993) found that when wives took care of husbands, the wives tended to minimize their own needs, but husbands, when providing caregiving services for their wives, became more aware of their own needs. The researchers recommended that interventions with caregivers should take gender differences in coping styles into account.

Many studies confirm that depression often accompanies caregiving. Coppel, Burton, Becker, and Fiore (1985) found depression to be a common, but usually untreated problem, of spousal caregivers of Alzheimer's disease patients. Most individuals in our society have brief episodes of depression, but long term untreated depression can increase morbidity and mortality (Reynolds, 1994). Caregiving of a dependent elder can continue for years. Bergman-Evans (1994b) reported caregivers have daily feelings of loss of personal control and strongly suggested health care workers suspect depression whenever a caregiver claims to have sleep problems.

Staight and Harvey (1990) used the Beck Depression Inventory and the UCLA Loneliness Scale to examine 50 female caregivers of spouses having mental and/or physical disabilities and found the caregivers suffered from depression, loneliness, financial worries, and low life satisfaction. Tennstadt, Cafferata, and Sullivan (1992) investigated depression in 415 caregivers and found one-third had depressive symptoms. A study by Hall et al. (1995) reported that care provided to a family member with Alzheimer's disease can be complicated by the presence of behavioral symptoms such as "agitation; waking at night confused and upset; the inability to recognize their home and/or their caregiver; belligerent and angry outbursts; attempts to wander; hallucinations and delusions; combative episodes; incontinence; suspiciousness; and poor communication." The behavioral problems of the dependent elderly person can lead to caregiver depression, burden, and breakdown. Anderson, Linto, and Stewart-Wynn (1995) studied 492 caregivers of long term stroke survivors and came to the conclusion that the caregivers had unmet needs related to their high level of emotional distress. In almost all instances, the caregivers of the stroke survivors reported adverse effects on their emotional health, social activities, and leisure time. Also, more than half of the caregivers of the stroke survivors reported negative effects on family relationships.

Depression can continue for the caregiver after the death of the elderly dependent. Former caregivers whose thoughts often returned to their past caregiving tasks were reported to be depressed, stressed, and socially isolated (Bodnar & Kiecolt-Glaser, 1994). Hegge (1991) found newly widowed caregivers to be troubled by loneliness and social isolation.

Caregiving can have an adverse economic impact upon the individual and family caring for a dependent elderly person. In a study focusing on the costs of caring for a demented elderly person, Stommel, Collins, and Givens (1994) reported that families contribute unpaid family labor, and also provide cash for equipment and services that will benefit the dependent elderly person. In another study it was found that financial difficulties can occur due to disrupted work patterns. Hogan (1990) reported on an intergenerational phenomenon in which single, female-headed families caring for elderly parents risk future poverty because of caregiving. Covinsky et al. (1994) examined the economic impact of caregiving upon 2,661 families of seriously ill persons (mean age 62 years old). In this report, many of the families faced extreme financial burdens as a result of caregiving. In some cases, a family member had to quit working to provide care to the seriously ill person; other families reported the loss of their major source of income, and other families reported loss of family savings.

Another problem for caregivers is the vulnerability to financial exploitation when unproven therapies are tried in an attempt to improve the condition of their dependent elderly person. In a study of 101 primary caregivers of people with Alzheimer's disease, Coleman, Fowler, and Williams (1995) found that 20% of the caregivers had tried 3 or more unproven therapies such as vitamins, health foods, herbal medicines, or "smart pills."

Two studies found the perceived caregiving burden could be associated with the amount of time required to care for the elder and the degree of debilitation of the elder (Harper & Lund, 1990; Novak & Guest, 1989). Ward (1990), in addition to reporting on the economic consequences of caregiving, analyzed that the amount of "free" time females devoted to caregiving should be one of the considerations in measurement of caregiving burden. Levine and Lawler (1991) reported on the negative impact caregiving had on the caregiver's leisure time, finances, and social activities.

Bergman-Evans (1994a) found loneliness and lack of social support to be a risk of spousal caregiving, and DesRosier, Catanzaro, and Piller (1992) reported females who were the primary caregivers of their husbands had strained marital relationships and feelings of social isolation. Morrisey, Becker, and Rupert (1990) also reported caregiving could have a negative impact on the caregiver's marriage.

Reinhard (1994), in a report on caregiving of the elderly mentally ill, reported caregivers felt burdened, helpless, and ignored by health care workers.

Caregiving burden was found to increase the risk of institutionalization of the dependent elder person (Cafferata & Stone, 1989; McFall & Miller, 1992). Elder abuse and neglect has been found to be another consequence of caregiver burden (Benton & Marshall, 1991; Coyne, Reichman, & Berbig, 1993; Fulmer, 1991). Abuse and neglect have been under-reported problems (Phillips & Rempusheski, 1986). Close family members, usually grown children of the elderly person, are the most likely to abuse the dependent parent, and elderly women are more likely to be abused than elderly men (Costa, 1993; Godlee, 1992; Williams-Burgess & Kimball, 1992). Also, partner abuse can occur when the spousal caregiver abuses the vulnerable spouse (Elliot, 1993). Coyne et al. (1993) reported that caregivers who had been in a caregiving situation for years to a low functioning dependent elder, were more likely to be assaultive toward the dependent elder than a caregiver who had only been in the caregiving situation a short time. In extreme cases of caregiver burden overload, "granny dumping" can occur. In this scenario, the elderly person is abandoned by the caregiver (Tanne, 1992; Wilson, 1992).

The caregiver, as well as the dependent elderly person, may have health problems as well as being elderly (Bull, Maruyama, & Luo, 1995; Caserta et al., 1987; Zarit, Orr, & Zarit, 1985). Caregiving places caregivers at risk for illness (DeMeneses & Burgess-Perry, 1993). Gaynor (1990) found that women who had been in a caregiving role a long time had more health problems than women who had acted in the caregiving role a short time. The health status of the caregiver can affect the caregiver's feeling of burden. Burden scores were found to be significantly related to caregiver health in data collected by Pratt, Schmall, and Wright (1986).

The caregiver's developmental difficulties revolve around restrictions on time and freedom, and employment consequences. The responsibilities of caregiving can affect long-term plans for retirement or plans to relocate to another area (Archbold, 1983; Chenoweth & Spencer, 1986). The impact of caregiving can also have a negative effect on the caregiver's professional career (Jutras & Veilleux, 1991).

Caregiver Burden Associated with ADL Care

There are a paucity of studies investigating the relationship of caregiving burden and the ADL performance status of dependent elderly persons. These studies also have conflicting results. Studies which found caregiving burden to be positively related to the ADL limitations of the dependent elderly person will first be discussed, followed by studies which did not find a correlation.

Deficits in the self-care abilities of a dependent elderly family member may result in the primary caregiver having feelings of burden as a sequel to the stressful demands of caregiving (Bull, 1990; Deimling & Bass, 1986; Farran, Keane-Hagerty, Tatarowicz, &

Scorza, 1993; Gretzel, 1982; Hadjistavropoulos, Taylor, Tuokko, & Beattie, 1994; Haley, Levine, Brown, & Bartolucci, 1987; Hooyman, Gonyea, & Montgomery, 1985; Montgomery, Gonyea, & Hooyman, 1985). For example, Miller, McFall, & Montgomery (1991) reported the more involved a caregiver was with the functional caregiving tasks of the dependent elder, the greater the caregiver stress. The stress was the result of caregiver fatigue from providing 24 hour caregiving services, as well as the restrictions that caregiving placed on the caregiver's personal time. Two studies (Bass, McClendon, Deimling, & Mukherjee, 1994; Poulshock & Deimling, 1984) reported that the inability to perform ADLs by community residing elderly persons could be a predictor of caregiver burden. The caregiving burden was the consequence of the restriction that caregiving placed on the caregiver's personal and social activities.

Morycz (1985) found that caregiving tasks involving physical labor, such as assistance with an elderly person's ADLs, increased caregiver strain and the likelihood of institutionalization of the dependent elderly person. In a study examining the relationship between caregiver burden and use of long term care services, a significant correlation between ADL ability of the older person and caregiving burden was recognized (Brown, Potter, & Foster, 1990).

Montgomery, Gonyea, et al. (1985) and Montgomery, Stull, and Borgatta (1985) found feelings of burden exist when caregiving tasks are extensive. Karmilovich (1994) found a correlation between the number and difficulty of helping behaviors a spousal caregiver of a person with heart failure performed and the level of caregiver stress and burden.

Stull, Kosloski, and Kercher (1994) reported caregiving burden was positively correlated with ADLs, elder cognitive impairment, and the number of caregiving tasks performed. Killeen (1990) provided data that caregivers of frail elderly persons who gave much care to the elderly family member reported high levels of stress. Grad and Sainsbury (1968) found that caregiving burden could be predicted when dependent persons with psychiatric problems were unable to perform self-care tasks. Motenko (1989) found that providing ADL care to a demented person was associated with the caregiver reporting increased frustration and decreased gratification.

Pearson et al. (1988), in a study of 46 caregivers, found caregiving burden to be significantly related to ADL limitations. There was also an interrelationship between disruptive behavior of the dependent elderly person with caregiver distress and caregiver burden. This study also provided data which indicated higher cognitive functioning of the older person had a positive interrelationship associated with fewer ADL limitations.

There were also studies that did not find impairments in an elderly person's ADL status to be correlated with caregiver burden (Drinka, Smith, & Drinka, 1987; Gilhooly, 1984; Zarit et al., 1980). Farran et al. (1993), in a study of 140 dementia caregivers, did not find ADL disability to be significantly correlated to caregiver burden, but caregiver burden was related to caregiver distress with these needs.

Summary

The review of the literature indicates there has been a paucity of research concerned with caregiver burden and the provision of ADL care for a dependent elderly person. Furthermore, the results have been equivocal. Researchers have provided theories for the inconsistencies in research outcomes and have presented several arguments to defend the ambiguity of results in the studies of the relationship of caregiver burden to the functional abilities of an elderly person.

George and Gwyther (1986) suggest that an attributable variable, caregiver well-being, was accountable for the difference in results of the studies. Pearson et al. (1988) theorized that the conflict in the results of the studies was due to the subjects being homogeneous groups, such as caregivers of elderly cognitively impaired persons, rather than heterogeneous groups. It was argued that caregiver burden is unique in each homogeneous group. Horowitz (1985) noted that emotional stress reported by caregivers did not always result in consistent findings in research studies. Montgomery (1993) hypothesized that caregivers go through stages of caregiving and at each level, the experience of burden is different. The stages are on a continuum which begins with the inception of caregiving tasks and ends with termination of the caregiving role. Montgomery (1989), in a review of the literature, reported that studies of caregiver burden have not used a uniform definition of caregiver burden. This nonconformity has prevented conceptual clarity and led to inconsistent research findings. Another group of researchers, Hadjistavropoulos et al. (1994), theorized that the reason caregiver burden is not affected by the dependent elderly person's functional ability is that the caregiver may find that the dependent person's self-care deficits are manageable by placing the dependent elderly person on a daily schedule of care.

A few studies have presented positive aspects of the caregiving experience, but the majority of caregiving studies indicate there are many negative consequences related to providing care for an aged family member. Females feel the effects of caregiving burden most often as they provide the bulk of the caregiving services to dependent, elderly persons. The financial burden of giving care can be catastrophic when family savings are depleted or when the caregiver is forced to quit working. Caregiving is most often provided in the home, and the caregiving tasks can continue and increase as time passes. Often, the caregiver is not only caring for the dependent elderly person, but is also caring for children. The long-term provision of caregiving tasks can cause psychological, physiological, sociocultural, and developmental stress which may negatively affect the well-being of the caregiver, and the ability of the caregiver to continue to provide effective care.

Orem's self-care deficit theory of nursing is the conceptual framework used in this study. The general theory has three constructs, self-care or dependent-care, self-care-deficit, and nursing systems. Orem emphasizes that self-care and dependent care tasks are learned activities. The nursing system construct can be utilized to improve the caregiver's self-care and dependent-care abilities.

Within the structure of the nursing system construct is the supportive-educative system of nursing care. In the supportive-educative system of nursing care, the caregiver receives nursing support such as teaching, guidance, provision of an environment focused on achieving health, or assistance in learning self-care measures. With a better understanding of the relationship between caregiver burden and an elderly care receiver's functional ability in activities of daily living, individualized interventions can be taught to the caregiver to decrease feelings of helplessness, to overcome perceived caregiving burden, to develop dependent-care techniques that will create a sense of competency, and to encourage the caregiver not to overlook personal needs.

Chapter 3

THE METHOD

This chapter presents the methodology used for the research study. The research design, sample, settings, instrumentation, procedures, and plan for analysis will be discussed.

The goal of the study was to explore the relationship between perceived caregiver burden and the ADL ability of the dependent elder. The study assessed the following research question: Is there a relationship between the level of deficit in activities of daily living of a dependent family elder to perceived caregiver burden?

Research Design

A non-experimental, descriptive, correlational design was used for this study. A survey method was employed as an efficient way to collect data that can only be provided by individual subjects (LoBiondo-Woods & Haber, 1990, pp. 167-168). No interventions were utilized to control or manipulate the participants. In this study, the dependent variable was perceived caregiver burden and the independent variable was the ADL ability of the dependent elder. Descriptive correlational research describes relationships among variables rather than inferring cause-effect relationships (Polit & Hungler, 1985, p. 114).

Approval to Conduct Study

Approval to conduct this study was first obtained from a community senior day center (see Appendix E). Approval was then obtained from the Human Subjects Institutional Review Board at

San Jose State University (see Appendix D). To increase the sample size, approval was obtained from a veterans administration hospital dementia respite center to conduct the study with caregivers of clients in the program. The proposal was approved by a university hospital panel on human subjects in medical research (see Appendix G) and a veterans administration hospital research department (see Appendix F). The Human Subjects Institutional Review Board at San Jose State University was informed of the addition of a site to the study (see Appendix L). All caregivers participating in the study signed consent forms, giving the researcher permission to use the data provided (see Appendix H for the consent form used at the senior day care center; see Appendix I for the consent form used at the hospital dementia respite program).

Sample

A convenience sample of 46 caregivers were approached to participate in the investigation. A list of 14 caregivers had been provided by the director of the senior day center, and a list of 32 caregivers had been provided by the social worker in charge of the hospital dementia respite program. The investigator contacted all persons on the 2 lists by telephone. The invitation to join in the study was extended to those persons who met the study criteria. The criteria for selection were the following: the person had to be the primary caregiver of a dependent family member, 50 years in age or older. The caregiver had to be 35 or more years of age, could be either male or female, could be a member of any culture, and should speak and read English. All 46 caregivers contacted met the study requirements.

Forty persons agreed to provide data for the investigation and signed a consent form. Fourteen subjects were caregivers of clients from the community senior day center and 26 subjects were caregivers of clients from the hospital dementia respite center. The six persons who declined were all caregivers of clients enrolled in the hospital dementia respite program. The reasons provided by the caregivers for their refusal to participate were personal health problems, time constraints, and unwillingness to disclose personal information.

Settings for the Study

Caregivers were solicited for the study from two settings. The two facilities are in the San Francisco Bay area in northern California. The first site was a community senior day center, and the second site was a hospital dementia respite program in a veterans administration hospital.

The senior day center, the first site of the study, features a structured, full day program for seniors who are not completely dependent. It is a non-profit, state-licensed adult day care center, and has been in operation since 1980. The senior day center receives partial funding from the United Way, the Council on Aging, Santa Clara County and two cities, and private donations. Fees for the clients are based on ability to pay with the average cost to the client being $19.00 per day. Elderly persons who wander, who are combative, or have unmanageable incontinence are excluded from attendance.

The senior day center is a pleasant and safe place for older adults requiring supervision and minimal care while family members are at work or feel the need for a day of respite from caregiving tasks. The program is designed to have the seniors stay alert and interested in life. Activities include reminiscing, classes in world travel, crafts, movement to music, cards, and board games. Lunch and snacks are served. Clients can attend on a regular daily basis during the week, or caregivers can arrange day care for a few hours a day when the need arises. The daily average attendance is 14 persons.

The hospital dementia respite program, the second study site, provides scheduled one to two week inpatient admissions to a locked, extended care unit for clients with dementia. Clients who attend the program are considered temporary patients. The respite program is offered only to veterans of the United States military services. The program can be utilized by the veteran for as many as 6 weeks a year and is intended to give respite to the home care provider.

The hospital is a large, full service facility, affiliated with a teaching hospital. Clients who attend the respite program have a history of wandering, are assaultive, are incontinent, and cannot verbalize their needs. At the dementia respite program, the veteran receives 24 hour medical observation, skilled nursing care, and can participate in many different types of recreational activities. A recreational director and an occupational therapist, with the assistance of nursing staff, arrange activities that are within the capabilities of the clients, such as exercise groups and simple arts and crafts. Picnics, walks, nerf ball toss, and bubble blowing are some of the outdoor activities that take place in the large, grassy enclosed patio attached to the dementia respite center building. At least one or more volunteer groups visit the dementia respite center weekly to play the piano, to put on a skit or dance performance, or to bring in pets for the client's enjoyment. A hospital chaplain provides a short nondenominational church service every Sunday.

A caregiver's group meets once a month, providing a time for mutual support, a time to network, and an opportunity to discuss problems and problem-solve. Also, social work staff instruct caregivers in the use of local community resources that can assist with caregiving difficulties. Overall, the hospital dementia respite program is designed to furnish the caregiver with temporary relief from caregiving, to teach the availability and use of community resources to assist with caregiving problems, to ease the burden of long term home care, and to delay placement of the elder in an institutional care setting (Berman et al., 1987).

Instruments

Data for this study were collected using three survey instruments. These tools were: (a) the Zarit Burden Interview, (b) the Index of Independence in Activities of Daily Living, and (c) a demographic tool. The instruments required self-report by the caregiver. The advantages of using self-report measures are that the subject personally completes the tool, less time is required from the researcher, and the researcher does not have to use subjective judgement as the scoring is standardized (Post et al., 1985). A description of each of the tools follows.

Zarit Burden Interview

The Zarit Burden Interview focuses on caregiver's feelings and experiences. This tool is one of the most frequently used instruments to measure caregiver burden (Mohide, 1993). It was originally a 29 item tool developed by Zarit, Reever, and Bach-Peterson in 1980 to evaluate the impact of caregiving upon the caregiver's social life, health, emotional well-being, and finances. In 1985, Zarit et al. published a 22 question revised Burden Interview (p. 84). The revised scale is used in this study and provides an estimate of the level of burden the caregiver is experiencing when taking the test. Results are rated on a 5 point scale: (a) never = 0 points, (b) rarely = 1 point, (c) sometimes = 2 points, (d) quite frequently = 3 points, and (e) nearly always = 4 points. Items are summed to yield a score between 0 and 88. The higher the score, the greater is the subjective burden of the caregiver.

Gallagher, Rappaport, Benedict, Lovett, and Silven (1985) estimated the internal reliability for the Burden Interview at .91 using Cronbach's alpha. The researchers also found the test/retest reliability to be .71. Dr. Zarit gave written permission to the primary investigator of this study to use the Zarit Burden Interview (see Appendix K).

Index of Independence in Activities of Daily Living

The Index of Independence in Activities of Daily Living (Katz, 1970) was developed to assess the functioning of the aged and chronically ill. It has had extensive use with older populations and is among the most widely used of the ADL scales (Pace, 1989). The instrument measures the performance of an elder to provide personal physical care. The six points used to evaluate the severity of deficits are bathing, dressing, going to the toilet, transferring, continence, and eating. The functions are commonly called activities of daily living (ADL). These functions are listed in the sequence in which dependency usually occurs, with the ability of the elder to feed the self being the last area in which independent functioning is lost (Frank-Stromberg, 1988, pp. 25-26).

The tool is graded by an observer by indicating one of 3 levels of performance on each of the six ADLs. The elder can carry out the activity as (a) completely independent, (b) can require assistance, or (c) can be unable, or refuse to perform the task. The data results are then converted into an Index of ADL (see Appendix M for ADL scoring key) by using a conversion table which is part of the instrument. This results in a hierarchical grade, A through G, where A is the most independent level along the continuum, and G is the most dependent level. There is also a level called "other." At this level, the elder is dependent in at least two functions, but not classifiable as C, D, E, or F. This category is reserved for the elderly person who can adequately perform a very basic function but not a less basic one. The person in this category is more dependent than a person in level A or B, but more independent than a person in level G (Ward & Lindeman, 1978, pp. 275-280). Scoring of the Index of ADL (Katz et al., 1970) is as follows:

A. Independent in feeding, continence, transferring, going to the toilet, dressing, and bathing.

B. Independent in all but one of these functions.

C. Independent in all but bathing and one additional function.

D. Independent in all but bathing, dressing, and one additional function.

E. Independent in all but bathing, dressing, going to toilet, and one additional function.

F. Independent in all but bathing, dressing, going to the toilet, transferring, and one additional function.

G. Dependent in all six functions.

Other: Dependent in at least two functions, but not classifiable as C, D, E, or F.

For the purpose of this study an additional level was added, level H. At this level, the elder is dependent in all but transferring. Level H is a subset from "G" category. Stolley (1994) described four stages of Alzheimer's disease: forgetful, confused, ambulatory dementia, and terminal. Level H was added as many of the dependent elders were in the third stage of Alzheimer's disease, which is ambulatory dementia. The addition of this level gave an increased insight to the researcher as to the functional ability of the dependent elder. Katz (1983), in a review of the progress that has been made in the measurement of ADL, explained that mobility and locomotion are basic self-maintenance functions and are now often included in measures of activities of daily living.

Katz et al. (1970) reported the validity of the Index of ADL was correlated with the Range of Motion Test and the Raven Test of intellectual function. Correlation with the Raven Test was .28, correlation with the Range of Motion Test was .55. Gallagher et al. (1985) estimated the internal reliability of the Index of ADL at .85 using Cronbach's alpha. The test/retest reliability was found to be .87. Written permission to use the Index of ADL for this study was received from Dr. Katz (see Appendix J).

Demographic Questionnaire

A demographic questionnaire (see Appendix C) was developed by the researcher and requested personal information about the dependent elder as well as personal information from the caregiver. The data collected by this tool were attribute variables and only used to describe the characteristics of the caregiver-care recipient dyads. The variables were chosen based upon a review of the literature. There was no attempt made in this study to investigate the relationship between the characteristics of the subjects and the dependent variable, perceived caregiver burden, or the independent variable, the ADL ability of the dependent elderly person.

The following questions were asked about the caregiver: age, relationship to the dependent elder, ethnicity, education, employment status, and annual family income. The questions asked about the dependent elder were age, gender, and possible behavior problems. In addition, there was a question asking if the care recipient had a diagnosis of Alzheimer's disease or dementia. The answer to this question was requested because care of those with dementia or Alzheimer's disease can be especially frustrating to the caregiver. This is due to the progressive and irreversible deterioration of the dependent elderly person as well as the dysfunctional behaviors which are often associated with the diagnosis (Hall, 1994).

Data Collection Procedures

Data for this study were collected over a 5 month period, May to September of 1995. The study was conducted at two sites: a senior day center and a hospital dementia respite program. Data were initially collected at the senior day center. Three months later, data collection began at the hospital dementia respite center.

At the first site, the senior day center, the agency sent an agency letter plus a letter from the researcher (see Appendix N) requesting caregivers to permit their names and addresses to be released to participate in the study. The senior day center approached the caregivers in this manner to protect the confidentiality of their clients. Fourteen caregivers signed the form giving the senior day center approval to release their names, addresses, and telephone numbers to the researcher. At the second site, the hospital dementia respite program, the researcher was given a list of all 32 clients currently enrolled in the program.

All caregivers were contacted by phone to request their participation in the investigation. Only primary family caregivers, caring for a dependent person who was 50 years of age or older, were accepted as subjects for the study. The caregiver could be male or female, be of any culture, should be able to speak and read English, and had to be 35 or more years of age. All caregivers contacted met this criteria.

The purpose of the study was explained to the caregiver during the initial phone conversation and any questions the caregiver voiced were answered. The caregivers were told that it should not take longer than 30 minutes to fill out the research forms, and any questions they did not wish to answer could be left blank.

All 14 of the caregivers from the senior day center agreed to participate, and 32 caregivers from the hospital dementia respite program agreed to participate. The consent to participate in the study was given voluntarily, without coercion.

A packet was mailed to all subjects containing an informed consent form, a demographic questionnaire, the Index of Independence of Daily Living, the Zarit Burden Interview, and a prepaid envelope addressed to the researcher. The tools and informed consent form in each of the packets were given an identifying number. When the completed packets were returned to the researcher, the informed consent was separated from the three tools and placed in a locked drawer. The informed consent was the only part of the packet that had the subject's name upon it.

Caregivers were asked to return the three tools and the informed consent in the prepaid envelope within 7 days. The primary researcher's phone number was prominently displayed on the research materials if the caregivers had any questions. Four subjects did phone, all from the hospital dementia respite program, with questions about the informed consent. The informed consent used for the hospital dementia respite program subjects was a small print, multi-page document which contained material required by the university hospital panel on human subjects in medical research and also material required by the veterans administration research department (see Appendix I). Each page had to be signed and dated by the potential subject. The form was generic in that it covered many types of human subjects research. The caregivers who phoned were confused about the nature of the study after reading the first page of the consent which stated, "This is to protect you from possible injury arising from such things as extra blood drawing, extra x-rays, interaction of research drugs, or similar hazards." The subjects were reassured by the researcher who explained there were not any medical procedures involved and reiterated the protocols of the study. The caregivers were also reminded of their right to withdraw from the investigation at any time. All four of the persons who phoned signed the informed consent and completed the research tools.

The majority of the research packets were returned within a week. If the researcher had not received the packet within 10 days, a follow-up phone call was made to the caregiver. All 14 caregivers from the senior day center and 26 of the 32 caregivers from the hospital dementia program returned the research material. Six caregivers from the hospital dementia program did not participate.

Confidentiality

The subjects were assured that confidentiality would be maintained and they would not be identified with the data. The data were reported as an aggregate. No names were placed on the instruments; rather, numbers were assigned to the subjects. The primary researcher was the only person with access to the identification list. This key to the numbering system was maintained in a locked cabinet, separate from the test materials, and was destroyed at the completion of the study.

Analysis Procedures to Interpret Data

In this study, the dependent variable is caregiver burden, and the independent variable is the ADL ability of the dependent elder. Statistical analysis of the relationship between the dependent and independent variables was computed using $p = .05$ as the level of significance of the Pearson product-moment coefficient. Descriptive statistics were also calculated on the demographic data to find frequency and mean. All data was analyzed by a statistician, using the Statistical Package for the Social Sciences (SPSS/PC+), Version 6.0, computer program. The next section presents a detailed analysis and interpretation of the data.

Chapter 4

ANALYSIS AND INTERPRETATION OF DATA

This chapter describes the data and the procedures used in analyzing the data. Data were collected to describe the caregiver and dependent elderly person dyad. Descriptive statistics were used to analyze data. Data were also collected to support or reject the two hypotheses: (a) a caregiver who provides a high level of activities of daily living care for a dependent elderly person as indicated on the Index of Independence in Activities of Daily Living (Katz et al., 1970) will report higher scores of perceived feelings of burden on the Zarit Burden Interview (Zarit et al., 1985; Zarit et al., 1980), and (b) a caregiver who provides a low level of activities of daily living care for a dependent elderly person as indicated on the Index of Independence in Activities of Daily Living (Katz et al., 1970) will report lower scores of perceived feelings of burden on the Zarit Burden Interview (Zarit et al., 1985; Zarit et al., 1980). Correlational statistics were used for analysis of the data collected. Additionally, the two subgroups of caregiver/care recipient dyads from the two sites were each analyzed to determine if there was a relationship between burden and the dependent elderly person's level of functioning in activities of daily living.

Demographic Data

Descriptive statistics comprised of frequencies, means, and percentages were used to compile a profile of the 40 caregiver and care receiver dyads. Tables 1 through 3 describe the demographic variables of the caregiver sample: Table 1, provides the gender, relationship to dependent elderly person, ethnicity, and highest educational level of the primary caregiver, Table 2, provides the ages of the primary caregivers, and Table 3, gives the employment profile of the primary caregiver, plus the family yearly income of the primary caregiver and care receiver dyad. Tables 4 and 5 provide the demographic variables of the dependent elderly persons. Table 4 gives the ages, gender, plus the number and percentage of elderly dependent persons with a diagnosis of dementia. Table 5 lists some of the behavior problems reported by the caregivers of the dependent elderly persons.

The convenience sample of 40 primary caregivers was composed of 35 (87.5%) female caregivers and 5 (12.5%) male caregivers (see Table 1). The caregiver's ages ranged from 43 to 82 years old with a mean of 66.2 years and a median of 69 years. The standard deviation was 10.5 (see Table 2).

Respondents were asked their relationship to the dependent elder for whom they were caring. Table 1 shows that 26 of the caregivers were wives (65%), 4 caregivers were husbands (10%), 8 caregivers were daughters (20%), 1 caregiver was a son (2.5%), and 1 caregiver was a sister (2.5%).

The sample population was predominantly Caucasian ($\underline{n}$ = 31, 77.5%). The next most frequently reported ethnic group was Afro-American ($\underline{n}$ = 6, 15%), followed by Hispanic ($\underline{n}$ = 3, 7.5%). None of the caregivers were of Asian or other racial group (see Table 1).

Table 1

Demographic Characteristics of Caregivers

Characteristic	Number	Percent
Gender		
Female	35	87.5%
Male	5	12.5%
Relationship to Dependent		
Wife	26	65.0%
Husband	4	10.0%
Daughter	8	20.0%
Son	1	2.5%
Sister	1	2.5%
Ethnicity		
Caucasian	31	77.5%
Afro-American	6	15.0%
Hispanic	3	7.5%
Asian/Other	0	0.0%
Highest Educational Level Attained		
Grade school	3	7.5%
High school	3	7.5%
High school graduate	7	17.5%
Partial university	10	25.0%
University graduate	8	20.0%
Post graduate	9	22.5%

Table 2

Ages of the Primary Caregivers

Caregiver Age	Frequency
43 to 50	4
51 to 60	8
61 to 70	10
71 to 80	16
81 to 85	2

M = 66.2

The data revealed a well educated group of caregivers. Twenty-seven of the participants (67.5%) were educated at the college level or beyond, and seven (17.5%) were high school graduates. Six (15%) of the subjects had not graduated from high school (see Table 1).

Table 3 gives a review of the caregiver's employment profile and yearly income. Only 10 caregivers (25%) were employed. Twenty-six (65%) were retired, and 3 (7.5%) did not work outside the home. The 3 caregivers who did not work outside the home were all female, one a wife (58 years old), and two were daughters (43 and 51 years old). The wife had a family income of less than $20,000 per year; the daughters both had family incomes above $50,000 per

Table 3

Employment and Yearly Income of the Primary Caregivers

Characteristic	Number	Percent
Employment Status (N = 40)		
Employed	10	25.0%
Retired	26	65.0%
Not employed	3	7.5%
Unreported	1	2.5%
Hours Employed (n = 10)		
20 to 35	2	
36 to 40	6	
41 to 50	1	
51 to 80	1	
Family Yearly Income (N = 40)		
Less than $20,000	9	22.5%
$20,000 to $35,000	11	27.5%
$35,000 to $50,000	5	12.5%
$50,000 and above	10	25.0%
No answer	5	12.5%

Table 4

Demographic Variables of the Dependent Elderly Persons

Characteristic	Number	Percent
Age		
65 to 75	20	50.0%
76 to 85	16	40.0%
86 to 95	3	7.5%
96 to 97	1	2.5%
Gender		
Male	27	67.5%
Female	13	32.5%
Diagnosis		
Dementia/AD diagnosis	32	80.0%
Undiagnosed	7	17.5%
Unanswered	1	2.5%

year. The one wife caregiver and one of the two daughters providing caregiving services reported that they would like to be employed outside the home if they did not have to care for the family elderly person.

More than half of the ten caregivers who were employed (n = 8) worked 40 or more hours a week. One caregiver reported working 80 hours a week which may be a reporting error by the subject.

The most frequently reported yearly family income level was \$20,000 to \$35,000 (n = 11, 27.5%). The second most frequently occurring family income was at the \$50,000 and above income level (n = 10, 25%). Nine caregivers (22.5%) were in the lowest income category, \$20,000 or less per year. Five subjects did not answer the question about the family yearly income (see Table 3).

The caregivers provided care for 27 male (67.5%) and 13 female (32.5%) elderly persons ranging in age from 65 years old to 97 years old. The median age was 75.5, the mean was 77.5, the standard deviation was 6.96 (see Table 4).

Thirty-two caregivers (80%) reported giving care to a person who had a diagnosis of dementia or Alzheimer's disease (AD). Seven caregivers (17.5%) said their elderly dependent had not been diagnosed with either Alzheimer's disease or dementia, and one caregiver (2.5%) did not respond to the question (see Table 4).

Problem Behaviors Reported

The primary caregivers of 32 (72%) family elderly persons reported one or more problem behaviors of the dependent elderly person which caused emotional strain for the caregiver and also increased the time the caregiver had to spend caring for the dependent person. Twenty (50%) of the care receivers resisted the care provided by their caregiver. Nineteen (47.5%) had wandered away from home and became temporarily lost. Eighteen of the

Table 5

Problem Behaviors of the Dependent Elderly Person

Behavior	Number	Percent
Resistive to care	20	50.0%
Wanders, gets lost	19	47.5%
Keeps family awake at night	18	45.0%
Episodes of cursing	10	25.0%
Yells and screams	10	25.0%
Assaultive	9	22.5%
Disrobes at inappropriate times	8	20.0%

Note: Eighteen care receivers (n = 45%) had 3 or more of the problem behaviors.

elderly persons (45%) kept the family awake at night. Twenty-five percent (n = 10) yelled or screamed. Ten elderly persons (25%) had episodes of cursing. Nine dependent elderly persons (22.5%) were assaultive toward family members. Eight elderly persons (20%) disrobed at inappropriate times. Eighteen care receivers (45%) had three or more of the problem behaviors (see Table 5).

Several of the caregivers wrote of additional problem behaviors of the dependent elder which the caregivers found disagreeable and made the caregiving task difficult: (a) "He follows me all day"; (b) "I have laundry problems, he needs frequent changes of clothes and bedding"; (c) "He fears anyone entering the home, and won't let children into the house"; (d) "He accuses me of stealing items he has misplaced"; (e) "He resists taking medication"; (f) "He urinates in public places"; (g) "He tries to take a shower but does not know how to adjust the water temperature. He turns on the water too hot"; (h) "He loses his dentures and glasses"; (i) "He gets confused when he is dressing and may change his shirt 4 to 5 times"; (j) "She accuses me of manhandling her when I am assisting her with walking"; (k) "She opens the windows at night which is a family security issue"; (l) "She talks incessantly and won't willingly stay alone in her room"; (m) "He has tantrums when he cannot express words or when I don't understand him"; (n) "He doesn't know who I am, he doesn't remember I am his wife"; (o) "He can't follow any directions"; and (p) "He will try to kiss strangers".

A caregiving husband wrote about his wife: "She has nobody but me. If I didn't take care of her she would die". One caregiving wife wrote, "I had plans for our retirement and it did not include taking care of a husband with Alzheimer's disease".

Interpretation of the Data

The objective of this study was to determine if there was a relationship between perceived caregiver burden and the dependent elderly person's ability to perform activities of daily living. The research question was: Is there a relationship between the level of deficit in activities of daily living of a dependent family elder to perceived caregiver burden? To answer the question, data from the Zarit Burden Interview (Zarit et al., 1985; Zarit et al., 1980) and the Index of Independence in Activities of Daily Living (Katz et al., 1970) were analyzed using the Pearson product-moment correlation coefficient.

Zarit Burden Interview Data (N = 40)

The Zarit Burden Interview evaluates the impact of caregiving upon the caregiver's social life, health, emotional well being, and finances. The instrument has 22 questions and estimates the level of burden the caregiver is experiencing. The tool has a 5 point rating system: (a) never = 0 points, (b) rarely = 1 point, (c) sometimes = 2 points, (d) quite frequently = 3 points, and (e) nearly always = 4 points. The items are summed to yield a score between 0 and 88. The higher the score, the greater is the subjective burden of the caregiver. The total scores for each of the caregivers in this study ranged from 13 points to 84 points. The median was 46 points.

In responding to the individual questions, 38 (95%) of the caregivers answered "quite frequently" or "nearly always" to the question, "Do you feel your relative is dependent on you?" Four other questions that the majority of caregivers gave the answer of "quite frequently" or "nearly always" were: (a) "Are you afraid of what the future holds for your relative?" ($\underline{n}$ = 29, 72.5%); (b) "Overall, how burdened do you feel in caring for your relative?" ($\underline{n}$ = 27, 67.5%); (c) "Do you feel that your social life has suffered because you are caring for your relative?" ($\underline{n}$ = 25, 62.5%); and (d) "Do you feel that your relative seems to expect you to take care of him/her, as if you are the only one he/she could depend on?" (n = 24, 60%). The three questions most frequently answered with "never" or "rarely" were: (a) "Do you feel you could do a better job in caring for your relative?" (n = 29, 72.5%); (b) "Do you feel that your relative asks for more help than he/she needs?" (n = 25, 62.5%) and (c) "Do you feel you should be doing more for your relative?" (n = 22, 55%).

To summarize the answers to the questions from the instrument, the caregivers strongly feel the elderly relative is dependent upon the care they provided, but this dependency is not perceived as a burden by the caregivers. As indication of this, the median of the burden scores from the Zarit Burden Interview was 46 points out of a possible 88 points.

Also, the answers to the Zarit Burden Interview indicate the caregivers have negative emotional consequences from the caregiving experience. The caregiver worries about the future of the care recipient. The dependent elderly person will not improve but is expected to deteriorate in health and functional ability. In addition, the caregiver's social life has been adversely affected from the provision of care to the elderly person, who depends on the caregiver and expects the caregiver to perform the caregiving tasks. However, to counteract these negative effects, the caregivers have positive feelings about the care they are providing to the dependent elderly person. The caregiver believes that the elderly family member does not ask for more help than is needed. The caregiver perceives that the caregiving duties performed for the elderly person are appropriate and the elderly person is receiving all the assistance that the caregiver can provide.

Index of Independence in Activities of Daily Living Data (N = 40)

The Index of Independence in Activities of Daily Living was developed to assess the basic functioning of the aged and chronically ill. Six functions, bathing, dressing, going to the toilet, transferring, continence, and feeding are graded as: (a) completely independent, (b) can require assistance, or (c) unable or refuses to perform task. The 6 functions, commonly called activities of daily living, are listed in the sequence dependence usually occurs. A conversion table, which is part of the instrument, is used to convert the data results into an Index of Activities of Daily Living (see Appendix M for ADL scoring key). The conversion table has 8 levels. A hierarchical grade, A through G, with A indicating independence and G complete dependence of the elderly person is produced. There is also a group called "other". At this level, the elderly person is dependent in at least 2 functions but not classified as C, D, E, or F.

The primary investigator of this study added a 9th category, H, which is a subset of group G. Group G elderly persons are dependent in all 6 functions. Group H are dependent in all 6 functions but are ambulatory. This group was added for information purposes. Groups G and H were scored the same as completely dependent elderly persons and did not change the possible maximum score.

In this study, 42.5% (n = 17) of the elderly persons were completely dependent on caregivers for all activities of daily living. This result is not surprising as 26 (65%) of the dependent elderly persons were from a veterans administration hospital dementia respite program that specialized in elderly clients who require maximum personal care in a locked setting, and who also have difficult to manage behavioral problems. Data from the study indicated 31 (77.5%) needed help with bathing and dressing. Bathing and dressing are two of the functions of activities of daily living that an elderly person is most often unable to perform. Twenty-seven (67.5%) were incontinent during the day and/or night. Twenty-three (57%) of the elderly family members needed assistance or reminders to use the toilet. The majority of the elderly persons (_n_ = 31, 77.5%) were able to completely or partially feed themselves. The ability to feed one's self is usually the last activity of daily living that a dependent person loses.

In summary, eleven dependent elderly persons were in the highest functioning ADL levels. At these levels, the dependent elderly person can be independent in ADL functioning or have up to 2 ADL disabilities. Twenty-two dependent elderly persons were in the lowest levels of ADL functioning. At these levels, there is a loss of 4 to 6 ADL functions. A 6 function loss is equal to complete dependence. Seven of the care receivers were categorized as having moderate loss of function.

Correlation Results (N = 40)

It was hypothesized that a caregiver who provides a high level of activities of daily living care for a dependent elder as indicated on the Index of Independence in Activities of Daily Living will report higher scores of perceived feelings of burden on the Zarit Burden Interview. It was further hypothesized that a caregiver who provides a low level of activities of daily living care for a dependent elder as indicated on the Index of Independence in Activities of Daily Living will report lower scores of perceived feelings of burden on the Zarit Burden Interview.

Statistical analysis using the Pearson product-moment correlation coefficient gave an r value of .218 which was not significant. Thus, there is no statistically significant relationship between perceived caregiver burden and the elderly dependent person's ability to perform the activities of daily living. Therefore the hypotheses are not supported.

Analysis of Individual Subgroups

The data were further analyzed by looking at the 2 subgroups, from the senior day center (n = 14) and the hospital dementia respite program (n = 26), to determine if there were any significant similarities or differences between the groups. The demographic information for the 2 groups is compared on Table 6. Table 7 compares the employment profile and yearly income level of the caregivers of the 2 groups. Also, an individual analysis of the data for each of the subgroups is provided.

Table 6

Demographic Comparison of Subgroups of Primary Caregivers

Characteristic	Senior Day Center (n = 14) Number	Percent	Hospital Respite (n = 26) Number	Percent
Gender of Caregiver				
Female	12	85.7%	23	88.5%
Male	2	14.3%	3	11.5%
Relationship				
Wife	4	28.6%	22	84.6%
Husband	2	14.3%	2	7.7%
Daughter	8	57.1%	0	0.0%
Son	0	0.0%	1	3.8%
Sister	0	0.0%	1	3.8%
Ethnicity				
Caucasian	13	92.9%	18	69.2%
Afro-American	0	0.0%	6	23.0%
Hispanic	1	7.1%	2	7.7%
Asian/Other	0	0.0%	0	0.0%
Highest Educational Level				
Grade school	1	7.1%	2	7.7%
High school	0	0.0%	3	11.5%
High school graduate	0	0.0%	7	26.9%
Partial university	7	50.0%	3	11.5%
University graduate	2	14.3%	6	23.0%
Post graduate	4	28.6%	5	19.2%
Gender of Dependent Person				
Female	10	71.4%	3	11.5%
Male	4	28.6%	23	88.5%

Note: Percentages may not total 100% because of rounding.

Table 7

Employment and Income Comparison of Primary Caregivers

Characteristic	Senior Day Center (*n* = 14) Number	Senior Day Center (*n* = 14) Percent	Hospital Respite (*n* = 26) Number	Hospital Respite (*n* = 26) Percent
Employment Status				
Employed	4	28.6%	6	23.1%
Retired	8	57.1%	18	69.2%
Not Employed	2	14.3%	1	3.8%
No Answer	0	0.0%	1	3.8%
Family Yearly Income				
Less than $20,000	1	7.1%	8	30.8%
$20,000 to $35,000	5	35.7%	6	23.1%
$35,000 to $50,000	1	7.1%	4	15.4%
$50,000 and above	6	42.9%	4	15.4%
No answer	1	7.1%	4	15.4%

Note: Percentages may not total 100% because of rounding.

Senior Day Center (n = 14)

The first group (*n* = 14) was solicited from a senior day center. The typical caregiver is a 61 year old daughter who is caring for her 81 year old mother. The caregiver is Caucasian, has had a partial university education, is retired, and has an income of $35,000 to

$50,000 per year. The dependent elderly person has a dementia diagnosis.

The Zarit Burden Interview scores in the subgroup n = 14 ranged from 20 to 64 with a mean of 43.6. The results of the Index of Independence in Activities of Daily Living had 6 dependent elderly persons with a high level of functioning in activities in daily living and 6 dependent elderly persons in the lowest functioning levels. The remaining 2 care receivers were classified as having a moderate loss of ADL functioning. The correlation of r = .1392 was statistically nonsignificant at the .05 level of significance for a relationship between perceived caregiver burden and the dependent elderly person's ability to perform activities of daily living.

Hospital Dementia Respite Program (n = 26)

The second group of caregivers (n = 26) was solicited from a hospital dementia respite program. The typical caregiver is a 68 year old wife who is caring for her 75 year old husband. The typical caregiver is Caucasian, has a partial university education, is retired, and has an income of $20,000 to $35,000 (median value) per year. Twenty-five of the 26 dependent elderly persons in this subgroup have a dementia diagnosis.

The Zarit Burden Interview scores in the hospital respite group ranged from 13 to 84 with a mean of 47.3. The results of the Index of Independence in Activities of Daily Living had 16 dependent elderly persons at the low level of functioning in activities of daily living and 5 dependent elderly persons in the higher functioning categories. The remaining 5 care receivers were at the moderate level of ADL functioning. The correlation of r = .230 was statistically nonsignificant at the .05 level of significance for a relationship between perceived caregiver burden and the dependent elderly person's ability to perform activities of daily living.

Summary of Subgroups

The demographic information indicated there were similarities and differences in the individual subgroup characteristics. In both groups the primary caregiver was a retired female, over the age of 60 years old, caring for an older individual with a dementia diagnosis. However, the primary caregivers of the dependent elderly persons from the senior day center were predominantly Caucasian daughters, with a university education, having an income of $35,000 or more, providing care for a mother. On the other hand, the caregivers from the hospital dementia program were predominantly wives with an income of $35,000 or less, having a high school education, and providing caregiving services for a husband.

The caregivers of the dependent elderly persons from the hospital dementia respite program were providing care for elderly persons who had a low level of functioning in the provision of personal activities of daily living. The caregivers of the dependent elderly from the senior day center were caring for dependent elderly persons with a high level of functioning in the provision of personal activities of daily living.

There was little difference in the scores of the Zarit Burden

Interview between the 2 subgroups. The score from the senior day center had a mean of 43.6 and the score from the hospital dementia respite program had a mean of 47.3. The Zarit Burden Interview has a scoring system that ranges from 0, which is equal to no burden, to 88, which is equal to a high level of burden. The 2 scores of the subgroups, 43.6 and 47.3, are in the midrange of burden level for the caregivers.

The correlation score between caregiver burden and the dependent elderly person's ability to perform activities of daily living was insignificant at $r = .1392$ for the senior day center and $r = .230$ for the hospital dementia respite program at the .05 level of significance.

Summary

This investigation had a descriptive correlational design which studied 40 caregivers. The subjects came from 2 facilities. Fourteen subjects came from a senior day center, and 26 subjects came from a hospital respite program. The demographic characteristics of the sample were examined. The data from the 2 self-report tools, the Index of Independence in Activities of Daily Living (Katz et al., 1970) and the Zarit Burden Interview (Zarit et al., 1985; Zarit et al., 1980) were analyzed for correlation using Pearson's product-moment correlation coefficient. Additionally, the 2 subgroups were individually analyzed. The results of the analysis of the sample and each of the 2 subgroups were nonsignificant at the p .05 probability level. Therefore, there was not a statistically significant relationship between caregiver burden and the functional ability of the dependent elderly person in activities of daily living for the entire sample or within either of the two subgroups.

Chapter 5

CONCLUSIONS AND RECOMMENDATIONS

This chapter presents a summary of the study. Conclusions and implications drawn from the study are discussed. Finally, recommendations are made for further research in the area of perceived caregiver burden.

Conclusions

The demographic information provided a profile of the caregiver-care recipient dyad. The study sample of 40 caregivers was described as predominantly Caucasian, elderly, well-educated, retired females with an income level of $20,000 to $35,000. The care recipients were predominantly husbands, who were older than their wives, and had a diagnosis of Alzheimer's disease. The caregivers reported many problem behaviors related to the dementia diagnosis of the elderly dependent person. The 2 most frequently reported troublesome behaviors of the dependent elderly persons were wandering away from home and getting lost (n = 19, 47.5%), and keeping the family awake at night (n = 18, 45%).

The study was a nonexperimental descriptive investigation using a survey method and correlational analysis. Two tools, the Index of Independence in Activities of Daily Living (Katz et al., 1970) and the Zarit Burden Interview (Zarit et al., 1985; Zarit et al., 1980) were utilized to obtain data to investigate if a relationship existed between perceived caregiver burden and the degree of assistance in activities of daily living provided to a dependent elderly person.

Using Pearson's product-moment coefficient for statistical analysis, the data were examined. The results were not statistically significant. Therefore, perceived caregiver burden was not related to the elderly dependent person's ability level to perform the personal activities of daily living. Conclusions of this study are specific to the subject population surveyed which was a convenience sample of caregivers from a veterans administration hospital respite program and a community senior day center.

Discussion

The findings of this study indicate that perceived caregiver burden is not affected by the dependent elderly person's ability or inability to perform the activities of daily living. In a secondary analysis of data collected from each site, there were no statistical significant relationships between perceived caregiver burden and the ADL level of the dependent elderly person for either location.

Thirty-seven of the 40 caregivers reported many problem behaviors of the dependent elderly person, such as resistance to care, wandering away from home and becoming temporarily lost, keeping the family awake at night, verbal abuse, and physically assaulting the caregiver. Many of the problem behaviors were voluntarily written in narrative form by the caregiver on the final page of the instrument packet. These negative behaviors were an inconvenience to the caregiver, causing emotional strain and increased the time the caregiver had to spend caring for the elderly family member. As problem behaviors of the dependent elderly person were not evaluated by the instruments used in this study, it can be inferred that the instruments were not sensitive to this variable which the caregivers considered annoying, and which could possibly have a consequence of perceived caregiver burden.

Studies of perceived caregiver burden in relationship to an elderly care-recipient's ability to perform the activities of daily living have had inconsistent results. The opinions of several researchers follow, providing their theories for the conflicting results.

Pearson et al. (1988) expressed the supposition that selection of subjects was the reason some studies had significant results while other studies had nonsignificant results in the relationship between caregiving burden and the activities of daily living ability of the dependent older family member. Rather than studying heterogeneous groups of caregivers as subjects, the groups of caregivers studied by researchers were most often homogeneous. For example, caregivers of dependent elders with psychiatric conditions, or caregivers of demented elders. Pearson et al. (1988) argued that caregiver burden may differ in each homogeneous caregiving group as each group had unique problems. The dilemma of a homogeneous sample affects this current study which used a convenience sample of caregivers who had similarities: they were primarily caring for dependent persons with Alzheimer's disease, and all the caregivers had periods of relief from caregiving tasks, either by having the dependent elderly person in the hospital respite program or by having the dependent elderly person attend the senior day center. The similarities of the caregiving subjects could have produced biased answers to the research questions and decreased the variation in responses.

Horowitz (1985) noted that in research studies, emotional stressors did not always result in consistent findings. "For most caregivers, these emotional strains come from a constant concern for the older person's health and safety and the need to redefine and come to terms with the changing nature of their relationship with the aging relative" (p. 208).

Hadjistavropoulos et al. (1994) theorized that caregivers may find that the dependent elderly person's self-care skill deficits are manageable simply by placing the dependent elderly person on a daily schedule of care. The researcher of this current study assumed that there would be a relationship between compromised physical functioning and diminished social functioning of a dependent elderly person with the burden perceived by the caregiver. This presumption was based on the notion that the physical exertion and time involved in providing care would be perceived as oppressive and an inconvenience by the person providing the care. Zarit et al. (1986) reported that exploration of the relationship of self-care agency in the ADL ability of an elderly person to the caregiving burden perceived by the caregiver has been minimal due to the assumption that caregiving burden can be predicted as the elderly person's functional ADL dependence on the caregiver increases.

An additional reason was submitted by George and Gwyther

(1986) for the difference in results of the studies. The two researchers believed an attributable process to be operating and proposed this process to be caregiver well-being. The conceptual rationale given by the researchers utilized measures in four domains to investigate the consequences of caregiving. The four domains were: (a) subjective and objective measures of physical health, (b) subjective and objective measures of social activities, (c) measures of financial resources and financial security, and (d) subjective and objective measures of mental health. Their study indicated that consequences of caregiving were more associated with caregiver well-being than were the illness idiosyncrasies of the dependent persons. This present investigation did not study in depth any of the four domains mentioned. The caregivers in this study, however, did have a hiatus from caregiving when the dependent elderly person attended the senior day center or when the dependent elderly person attended the hospital dementia program. The intermission from providing full time care would provide the caregiver with time for personal and social activities. Thus, in this study, the variable of caregiver well-being most likely is positively effected.

Montgomery (1993) has outlined a framework of 7 caregiving stages and proposes that studies of caregiving burden should identify the level the caregiver has attained to prevent contradictory research results. The parameters of the stages extend from the inception of caregiving tasks to the death or recovery of the elderly person. Not all caregivers go through all 7 stages. Montgomery

(1993) hypothesizes that a caregiver's needs and experience of burden is different at each stage. The 7 markers of caregiving are: (a) inception of caregiving tasks, (b) defining self as caregiver, (c) providing personal care, (d) caregiver seeks assistance and formal service use, (e) consideration of nursing home placement, (f) nursing home placement, and (g) termination of caregiving role. This present study did not utilize Montgomery's (1993) framework of caregiving stages, although due to using a convenience selection of subjects from a hospital dementia respite program and a senior day center, it is known that all the caregivers had arrived at the stage of seeking assistance and formal service use.

Although there have been many studies about the burden experienced by caregivers, precise measurement of perceived caregiving burden has been elusive. Montgomery (1989), in a review of the literature on caregiver burden, noted that studies in this area have "been conducted with little theoretical guidance and a lack of consensus as to the meaning of key terminology." For instance, for some groups of researchers caregiver burden was defined as the "load or responsibilities" borne by the caregiver. Other groups of researchers defined caregiver burden as "something oppressive," a third group of researchers combined the two definitions. Yet other groups of researchers have used "caregiver strain, costs of care, family inconvenience, caregiving consequences, personal strains, stress effects and caregiving impact, and caregiving well-being" in studies of caregiving burden. This current study defined caregiver burden as "the extent to which caregivers perceived their emotional or physical health, social life, and financial status as suffering as a result of caring for their relative" (Zarit et al., 1986). The myriad of definitions used to investigate caregiver burden has prevented conceptual clarity and led to nonuniform findings.

Implications

The cumulative effect of declining death rates combined with improvements in medical technology have led to an increase in persons over the age of 65 years old in our society. This changing proportion of older people to younger people is expected to continue to increase during the next 25 years and has become a national concern in the light of political pressure to decrease government expenditures for health care. Current federal, state, and local policies have placed an increasing emphasis on home caregiving (Barnes, Given, & Given, 1992). Many of those over the age of 65 are unable to provide for personal self-care related to problems with physical and mental functioning. The decline in health and social circumstances of the elderly person may require the assistance of another to provide caregiving services. As in this present study, the person who takes on the duties of caregiver is most often female, and a member of the elderly person's family.

The literature review revealed that the provision of care to an elderly dependent person can often be challenging and may have negative consequences for the caregiver. The greater the elderly person's disability, the greater will be the physical dependence on the caregiver (Crossman & Kaljean, 1984). Caregiver support is an important factor in maintaining a dependent elderly person in the community. One possible sequel of providing the activities of daily living for the dependent elderly person can be perceived caregiver burden. Since family caregivers are the main source of care and support for aging dependent persons, their physical and emotional health should be protected. The family caregiver who has perceptions of burden has need of assistance. Nursing and social service interventions can provide support for the caregiver to decrease the perception of burden and help the caregiver successfully meet the challenges of caregiving. This help is crucial to postpone the placement of the dependent elderly person in an institution.

Orem's (1980; 1985) self-care deficit theory of nursing was selected as the theoretical basis for this study. The possible perceived burden associated with the care of a dependent elderly person can have an effect on the self-care and dependent-care ability of the caregiver. Managing the caregiving needs of caregivers is an area where nursing agency can make a difference. Nurses, utilizing the supportive-educative function of Orem's (1980; 1985) self-care deficit theory of nursing, are in a position to assist the caregiver with caregiving strategies and to discuss the need and use of social services for the family.

The nurse-agent, in a partnership with the caregiver, can assess and evaluate the social, psychological, and physical resources of the caregiver to devise an appropriate support and referral program. The nurse-agent provides knowledge and skill to support, guide, educate, care, and to establish an environment conducive to the health of the caregiver as a dependent-care agent. The nurse-agent is the instrument to aid the caregiver to become cognizant that dependent-care does not have to be provided at the expense of personal physical and emotional well-being, and to assist the caregiver to develop skills to adapt to the role of the caregiver. In the supportive-educative role, the assistance of the nurse-agent is beneficial to both the caregiver and the care recipient. The nurse-agent teaches the self-care and dependent-care methods that are a means to encourage the caregiver-care receiver dyad to learn and perfect caregiving tasks, to develop an awareness of available social services to make home-based care easier, and to minimize family dysfunction.

The relationship between perceived caregiver burden and the functional ability in activities of daily living of a dependent elderly person is complex and multidimensional, and is difficult to study. An example of this is the contradictory findings of previous research studies. Additionally, researchers have not identified a universal definition for caregiver burden. Another research concern is the multiple variables which affect studies of caregiving. The life of the caregiver is strongly intertwined with the the life of the care receiver. Ethnicity, duration of caregiving, gender of caregiver, relationship of caregiver to care-recipient, type of disability of the dependent person, financial resources, and social supports of the caregiver are just a few of the associations that can affect the caregiving experience. Although caregivers share similarities, there is tremendous diversity in their experience.

Recommendations

Recommendations for future studies include:

1. Future research on the relationship between the ADL ability of a dependent elderly person and perceived caregiver burden would benefit from a more detailed demographic exploration of individual variations of the caregiver and care recipient.
2. Future studies should investigate if caregiver burden is affected by the diagnosis of the dependent elderly person.
3. Future studies should have a larger, more randomized sample. The study could examine the variation in caregiver burden in culturally diverse groups or by geographic location.
4. If this study is replicated, it is recommended that a depression scale, such as the Beck's Depression Inventory (Beck, Ward, Mendelson, Mock, & Ebaugh, 1961), also be administered along with the Zarit Burden Interview (Zarit et al., 1980; Zarit et al., 1985) to get additional information about the caregiver's emotional state and response to the caregiving experience. This is also a recommendation of Zarit et al. (1985).

Summary

As family caregivers will continue to provide the majority of care in the home for dependent elderly persons, it is recommended that the nursing profession increase involvement with the caregivers by teaching caregiving skills to enhance caregiving ability and to identify and deal with individualized stresses. Nurse-agents can provide education, support, reassurance, and referrals. Increased attention should be focused on programs, such as day care or respite programs, to facilitate continued noninstitutional residence of the dependent elderly person.

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Appendix A

Zarit Burden Interview

Code #______

Zarit Burden Interview

INSTRUCTIONS: The following is a list of statements which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way:

0=Never 1=Rarely 2=Sometimes 3=Quite Frequently 4=Nearly Always

There are no right or wrong answers.

1. Do you feel that your relative asks for more help than he/she needs?

0 1 2 3 4

2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?

0 1 2 3 4

3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?

0 1 2 3 4

4. Do you feel embarrassed over your relatives behavior?

0 1 2 3 4

5. Do you feel angry when you are around your relative?

0 1 2 3 4

Code #_________

0=Never 1=Rarely 2=Sometimes 3=Quite Frequently 4=Nearly Always

6 Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?

0 1 2 3 4

7. Are you afraid what the future holds for your relative?

0 1 2 3 4

8. Do you feel that your relative is dependent on you?

0 1 2 3 4

9. Do you feel strained when you are around your relative?

0 1 2 3 4

10. Do you feel your health has suffered because of your involvement with your relative?

0 1 2 3 4

11. Do you feel that you don't have as much privacy as you would like because of your relative?

0 1 2 3 4

12. Do you feel that your social life has suffered because you are caring for your relative?

0 1 2 3 4

Code #__________

0=Never 1=Rarely 2=Sometimes 3=Quite Frequently 4=Nearly Always

13. Do you feel uncomfortable about having friends over because of your relative?

0 1 2 3 4

14. Do you feel that your relative seems to expect you to take care of him/her, as if you are the only one he/she could depend on?

0 1 2 3 4

15. Do you feel that you don't have enough money to care for your relative, in addition to the rest of your family?

0 1 2 3 4

16. Do you feel that you will be unable to take care of your relative much longer?

0 1 2 3 4

17. Do you feel that you have lost control of your life since your relative's illness?

0 1 2 3 4

18. Do you wish that you could just leave the care of your relative to someone else?

0 1 2 3 4

Code #__________

0=Never 1=Rarely 2=Sometimes 3=Quite Frequently 4=Nearly Always

19. Do you feel uncertain about what to do about your relative?

0 1 2 3 4

20. Do you feel you should be doing something more for your relative?

0 1 2 3 4

21. Do you feel you could do a better job in caring for your relative?

0 1 2 3 4

22. Overall, how burdened do you feel in caring for your relative?

0 1 2 3 4

Appendix B

Index of Independence in Activities of Daily Living

Code #_____

Index of Independence in Activities of Daily Living
(Index of ADL)

INSTRUCTIONS: For each area of functioning, check the description that best applies to the elder for which you provide care.

The word "assistance" means supervision, direction, or personal assistance.

1. **BATHING**--either sponge bath, tub bath, or shower

_____Receives no assistance (gets in and out of tub by self if tub is usual means of bathing).

_____Receives assistance in bathing only one part of the body (such as back or a leg).

_____Receives assistance in bathing more than one part of the body (or not bathed).

Code #_________

2. **DRESSING**--gets clothes from closets and drawers including underclothes, outer garments, and uses fasteners (including braces, if worn).

_____Gets clothes and gets completely dressed without assistance.

_____Gets clothes and gets dressed without assistance except for assistance in tying shoes.

_____Receives assistance in getting clothes or in getting dressed or stays partly or completely undressed.

3. **TOILETING**--goes to the "toilet room" for bowel and urine elimination; cleaning self after elimination, and arranging clothes.

_____Goes to "toilet room", cleans self, and arranges clothes without assistance (may use object for support such as cane, walker, or wheelchair and may manage night bedpan or commode, emptying same in the morning.

_____Receives assistance in going to "toilet room" or in cleansing self or in arranging clothes after elimination or in use of night bedpan or commode.

_____Doesn't go to the room termed "toilet" for the elimination process.

Code #_________

4. **TRANSFER**

_____Moves in and out of bed as well as in and out of chair without assistance (may be using object for support such as cane or walker).

_____Moves in or out of bed or chair with assistance.

_____Doesn't get out of bed.

5. **CONTINENCE**

_____Controls urination and bowel movement completely by self.

_____Has occasional "accidents".

_____Supervision helps keep urine or bowel control; catheter is used or is incontinent.

6. **FEEDING**

_____Feeds self without assistance.

_____Feeds self except for getting assistance in cutting meat or buttering bread.

_____Receives assistance in feeding or is fed partly or completely by using tubes or intravenous fluids.

Appendix C

Demographic Questionnaire

Code #________

DEMOGRAPHIC INFORMATION

CAREGIVER INFORMATION: It is not necessary to answer any questions that make you feel uncomfortable.

1. **Caregiver Age**_____________

2. **Relationship to Dependent:**
   - Wife________________
   - Husband______________
   - Mother______________
   - Father_______________
   - Friend_______________
   - Other (Please explain) ______________________

   ____

3. **Ethnicity**
   - Caucasian_____________
   - Afro-American_________
   - Asian_________________
   - Hispanic______________
   - Other_________________

4. **Education**--check highest level attained.
   - Grade School_______________
   - Junior High School__________
   - High School _______________
   - High School Graduate________
   - Partial University___________
   - University_________________
   - Post Graduate______________

Code #____________

5. **Employment**

Yes________ How many hours weekly?_________

No_________ Retired__________

Would you be employed outside the home if you did not have to care for your dependent elder?

Yes________

No_________

6. **Family Income per year**

$20,000/year or less____________

$20,001 to $35,000_____________

$35,001 to $50,000_____________

$50,001 or above_______________

7. Has the diagnosis of dementia or Alzheimer's Disease been applied to your dependent elder?

Yes__________

No___________

Code #________

Demographic Information

DEPENDENT ELDER INFORMATION

1. **Age of dependent elder**__________

2. **Male**______ **Female**_______

3. **Does the dependent elder have behavior problems which makes care difficult?**
Check all problems that apply.

Keeps family awake at night_______
Assaultive _______________
Resistive to care____________
Disrobes at inappropriate times_____________
Yells and/or screams_________________
Episodes of cursing_______________
Wanders, gets lost___________________
Other____
____

Appendix D

Human Subjects Approval: San Jose State University

SAN JOSE
STATE
UNIVERSITY

A campus of The California State University

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

TO: Laura Bour
21434 Shannon Ct.
Cupertino, CA 95014

FROM: Serena W. Stanford
AAVP, Graduate Studies & Research

DATE: April 17, 1995

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

"Dependent Elder Care: The Impact on Caregiver Burden"

This approval is contingent upon the subjects participating in your research project being approriately 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 pariticpation 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 me at (408) 924-2480.

Appendix E

Site Approval: Senior Day Center

CUPERTINO
CSDS
SENIOR DAY SERVICES

John T. Timbs, Executive Director
Cupertino Sunnyvale Senior Day Services
Day Care Centers for the Elderly
P.O. Box 622
Cupertino, CA 95015

March 27, 1995

Laura M. Bour
21434 Shannon Court
Cupertino, CA 95014

Dear Mrs. Bour:

I have been informed of your intent to conduct a nursing study at the Cupertino and Sunnyvale Senior Day Centers entitled Dependent Elder Care: The Impact on Caregiver Burden. I understand that participation in the study is completely voluntary and the anonymity of the seniors and their caregivers will be maintained. The study will be conducted over the next eight months, April to December, 1995.

I hereby give permission to Laura M. Bour to collect data at the Cupertino and Sunnyvale Senior Day Centers.

Sincerely,

John T. Timbs

John T. Timbs
Executive Director

P O. Box 622, Cupertino, CA 95015 (Located at St. Jude's Episcopal Church, Stelling & McClellan, Cupertino) (408) 973 0905

Appendix F

Site Approval: Hospital Dementia Respite Program

Department of Veterans Affairs

Memorandum

Date : October 10, 1995
From : Research Administration (151A)
Subj : Approval of Research Proposal
To : Laura M. Bour (123C-MPD)

1. Your research program entitled, Dependent Elder Care: The Impact on Caregiver Burden was approved at the Research and Development meeting of September 28, 1995. I plan to start work on this project August 26, 1995 (date). Please complete and return to (151A). Thank you.

2. The results of this review are as follows:

X Approved as written
____ Approved, pending changes or clarification (you will be contacted on this)
____ Tabled for future review (you will be contacted on this)
____ Disapproved (you will be contacted on this)

3. **BY VA LAW,** you must submit an INITIAL, and thereafter, annual PROGRESS reports on all research in which you participate, whether the research is VA-funded, non-VA-funded, or non-funded.

Laura M. Bour, RNC
PI Signature

10-25-95
Date

Evelyn
Evelyn Willcox
Program Assistant
x65111

Department of Veterans Affairs

Memorandum

Date : August 23, 1995

From : AA. Research Administration (151A)

Subj : Approval of Project

To : Joni Robick, RN (323C)

1. This is to notify you of approval of the project, "Dependent Elder Care: The Impact on Caregiver Burden", principal investigator Laura Bour, RN.

2. Formal approval will be documented in the minutes of the Research and Development Committee meeting of September 21; however, administrative approval granted by Dr. Marguerite Hays, ACOS, R&D is effective immediately, and the project may be begun at any time.

3. Please call me if you have any questions or concerns not addressed herein.

Shilo Herrling
x5571

Appendix G

Human Subject Approval: Hospital

STANFORD UNIVERSITY
Stanford, California 94305
(415) 723-5244

CERTIFICATION OF HUMAN SUBJECTS APPROVAL

DATE August 1, 1995

TO: L.M. Scur, R.N.
Department of Nursing Service

FROM: Chairman, Administrative Panel on
Human Subjects in Medical Research

PROTOCOL ENTITLED:
Dependent Elder Care: The Impact on Caregiver Burden.

The Panel approved human subject involvement in your research project on August 1, 1995.

The expiration date of this approval is July 31, 1996. If this project is to continue beyond that date, please submit an updated proposal in advance for the Panel's re-approval. If this proposal is used in conjunction with any other human experimentation or if it is modified in any way, it must be re-approved for these special circumstances. In addition, the Panel requests prompt notification of any complications which may occur during any experimental procedure.

All continuing projects and activities must be reviewed and re-approved at least annually by the Panel. Panel approval of any project is for a maximum period of one year. It is the responsibility of the investigator to resubmit the project to the Panel for annual review.

Alice Haskett
for James Theodore, M.D., Chairman

cc: M. Hays, M.D.

Funding Agency: (VA Study)(N)
Period of Time: 08/01/95 through 07/31/96
Investigational New Drugs: N
Investigational New Device: N
Cooperating Institution: N
Expedited Review
Assurance Number: M1272
IRB #01

Appendix H

Consent Form: Senior Day Center

SJSU SAN JOSE STATE UNIVERSITY
A campus of The California State University

College of Applied Sciences and Arts • Department of Nursing
One Washington Square • San Jose, California 95192-0057 • 408/924-3130 • FAX 408/924-3135

AGREEMENT TO PARTICIPATE IN RESEARCH

Responsible Investigator--Laura Bour, RN,C 408-253-2687
Title of Protocol--Dependent Elder Care: The Impact on Caregiver Burden

You are invited to participate in a study which will investigate if a dependent elder's ability or inability to perform daily personal care activities has an effect on caregiver perceived feelings of burden. There will be no risks to you. If you agree to participate in the study, you will be asked to complete 3 questionnaires that will not take longer than 30 minutes to answer.

Your responses will be coded to the data and maintained in an anonymous manner. The code and individual responses will be destroyed at the end of this study. Results of this study may be published and data will be presented in an aggregate. Individual names will not be associated with the data. You will receive no monetary compensation for your participation. You are free to quit the study at any time without prejudice to your relationship with the Cupertino-Sunnyvale Senior Day Services or San Jose State University.

While there is not likely to be any direct benefit to you, your participation can make a meaningful contribution to increase the understanding of the problems of caregiving.

Questions about the research can be addressed to Laura Bour, 408-253-2687. Complaints about the research can be addressed to Dr. Gorenberg, Director of the School of Nursing, 408-924-3130. Questions or complaints about research or subjects' rights may be presented to Serena Stanford, Ph.D., Associate Academic Vice President for Graduate Studies and Research, at 408-924-2480.

YOUR SIGNATURE ON THIS DOCUMENT INDICATES AGREEMENT TO PARTICIPATE IN THE STUDY. A COPY OF THE CONSENT FORM WILL BE GIVEN TO YOU.

....
Subject's Signature Date

....
Investigator's Signature Date
Signature of researcher indicates agreement to include the above named subject in the research and attestation that subject has been informed of his or her rights.

Appendix I

Consent Form: Hospital Dementia Respite Program

Title of Protocol: Dependent Elder Care: The Impact on Caregiver Burden

Are you participating in any other research studies? ____Yes ____No

INFORMED CONSENT

You are invited to participate in a study of caregiver burden. I hope to learn if a caregiver who provides a high level of personal care for an elder will report elevated feelings of perceived caregiving burden. You were selected as a possible participant in this study because you are a caregiver of a family elder.

If you decide to participate, you will be asked to complete 3 questionnaires that will not take longer than 30 minutes to answer. You will be given a stamped, addressed envelope in which to return the completed questionnaires to the investigator, Laura Bour, RN,C BSN. No risks are anticipated. Your responses will be coded to the data and maintained in an anonymous manner.
WE CANNOT AND DO NOT GUARANTEE OR PROMISE THAT YOU WILL RECEIVE ANY BENEFITS FROM THIS STUDY.

You will be told if any new information is learned which may affect your condition or influence your willingness to continue participation in this study.

While participating in this study, you should not take part in any other research project without approval from the investigators. This is to protect you from possible injury arising from such things as extra blood drawing, extra xrays, interaction of research drugs, or similar hazards.

Any data that may be published in scientific journals will not reveal the identity of the subjects. Patient information may be provided to Federal and regulatory agencies as required. The Food and Drug Administration, for example, may inspect research records and learn your identity if this study falls within its jurisdiction.

No payment will be provided for participation in this project.

There will be no cost to participate in this study.

The investigator, Laura Bour, RNC, is providing financial support and materials for the study. San Jose State University is involved in the study in an advisory capacity in association with the Masters Degree in Nursing Program.

______________________________ ____________
Signature Date

______________________________ ____________
Signature of Investigator or Witness Date

Title of Protocol: Dependent Elder Care: The Impact on Caregiver Burden

Your decision whether or not to participate will not prejudice you or your medical care. If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without prejudice to you or effect on your medical care.

At the discretion of the principal investigator subjects may be taken out of this study.

If you have any questions, I expect you to ask me, Laura Bour, at 408-253-2687. If you have any additional questions later, Dr. Ann Doordan, my advisor, at (408) 924-3157 or Dr. Serena Stanford, Associate Academic Vice President for Graduate Studies and Research at San Jose State University, (408) 924-2480 will be happy to answer them.

In the unlikely event you are injured as a result of participation in this study, Palo Alto Veterans Administration Medical Center will furnish humanitarian emergency medical care (for non-veteran participants) or medical care (for veteran participants) as provided by federal statute. Compensation for such injury may be available to you under the provision of the Federal Tort Claims Act and/or 38 U.S.C. section 1151 (formerly section 351) (for veteran participants only). For further information, contact the V.A. District Counsel at (415) 744-7676.

All forms of medical diagnosis and treatment--whether routine or experimental--involve some risk of injury. In spite of all precautions, you might develop medical complications from participating in this study. If such complications arise, the researchers will assist you in obtaining appropriate medical treatment, but this study does not provide financial assistance for additional medical or other costs. [Additionally, Stanford is not responsible for research and medical care by other institution's initiations or personnel participating in this study.] You do not waive any liability rights for personal injury by signing this form. For further information, please call (415) 723-5244 or write Stanford University, Administrative Panel on Human Subjects in Medical Research, 1215 Welch Road, Palo Alto, CA 94304-5532. In addition, or if you have any questions concerning your rights as a study participant, please contact the Human Subjects Office at the same address and telephone number.

______________________________ ________________
Signature Date

______________________________ ________________
Signature of Investigator or Witness Date

Title of Protocol: Dependent Elder Care: The Impact on Caregiver Burden

As a human subject, you have the following rights. These rights include, but are not limited to, the subject's right to:

-be informed of the nature and purpose of the experiment;

-be given an explanation of the procedures to be followed in the medical experiment, and any drug or device to be utilized;

-be given a description of any attendant discomforts and risks reasonably solvable to be expected;

-be given an explanation of any benefits to the subject reasonably to be expected, if applicable;

-be given a disclosure of any appropriate alternatives, drugs or devices that might be advantageous to the subject, their relative risks and benefits;

-be informed of the avenues of medical treatment, if any available to the subject after the experiment if complications should arise;

-be given an opportunity to ask questions concerning the experiment or the procedures involved;

-be instructed that consent to participate in the medical experiment may be withdrawn at any time and the subject may discontinue participation without prejudice;

-be given a copy of the signed and dated consent form;

-and be given the opportunity to decide to consent or not to consent to a medical experiment without the intervention of any element of force, fraud, deceit, duress, coercion or undue influence on the subject's decision.

YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION, THAT YOU HAVE DISCUSSED THIS STUDY WITH THE PRINCIPAL INVESTIGATOR AND HIS OR HER STAFF, THAT YOU HAVE DECIDED TO PARTICIPATE BASED ON THE INFORMATION PROVIDED, AND THAT A COPY OF THIS FORM HAS BEEN GIVEN TO YOU.

______________________________ Signature
______________ Date

______________________________ Signature of Investigator or Witness
______________ Date

______________________________ Approval Date
______________ Expiration Date

SJSU SAN JOSE STATE UNIVERSITY
A campus of The California State University

College of Applied Sciences and Arts • Department of Nursing • Nurse Managed Centers
One Washington Square • San José, California 95192-0057 • 408/924-3181 • FAX 408/924-3135

AGREEMENT TO PARTICIPATE IN RESEARCH

Responsible Investigator--Laura Bour, RN,C BSN (408) 253-2687
Title of Protocol--Dependent Elder Care: The Impact on Caregiver Burden

You are invited to participate in a study which will investigate if a dependent elder's ability or inability to perform daily personal care activities has an effect on caregiver perceived feelings of burden. There will be no risks to you. If you agree to participate in the study, you will be asked to complete 3 questionnaires that will not take longer than 30 minutes to answer.

Your responses will be coded to the data and maintained in an anonymous manner. The code and individual responses will be destroyed at the end of this study. Results of this study may be published and data will be presented in an aggregate. Individual names will not be associated with the data. You will receive no monetary compensation for participation. You are free to quit the study at any time without prejudice to your relationship with the VA Medical Center or San Jose State University.

While there is not likely to be any direct benefit to you, your participation can make a meaningful contribution to increase the understanding of the problems of caregiving.

Questions about the research can be addressed to Laura Bour, (408) 253-2687. Complaints about the research can be addressed to Dr. Gorenberg, Director of the School of Nursing, (408) 924-3130. Questions or complaints about research or subjects' rights may be presented to Serena Stanford, Ph.D., Associate Academic Vice President for Graduate Studies and Research, at (408) 924-2480.

YOUR SIGNATURE ON THIS DOCUMENT INDICATES AGREEMENT TO PARTICIPATE IN THE STUDY. A COPY OF THE CONSENT FORM WILL BE GIVEN TO YOU.

Subject's Signature   Date

Investigator's Signature   Date

Signature of researcher indicates agreement to include the above named subject in the research and attestation that subject has been informed of his or her rights.

Appendix J

Permission to Use the Tool:

Index of Independence in Activities of Daily Living

Dear Ms. Bour.
Please feel free to
use the Index of ADL
for your thesis.
Good Luck.

Sincerely
S. Katz

Laura M. Bour
21434 Shannon Court
Cupertino, CA 95014

February 11, 1995

Dr. Sidney Katz
7525 Racebrook Road
Gates, Ohio 44040

Dear Dr. Katz:

I am a master's degree student in the nursing program at San Jose State University. One of the requirements for the degree is to complete a research thesis.

The study I proposed for my thesis concerns the identification of activities of daily living, provided to a dependent elder by a caregiver, which may be factors in perceived burden in the caregiver.

I would appreciate your written permission to use the Index of Independence in Activities of Daily Living (Index of ADL) to determine the level of care a caregiver is providing to a dependent.

Sincerely,

Laura M Bour

Laura M. Bour, RN,C BSN

Appendix K

Permission to Use Tool: Zarit Burden Interview

Laura M. Bour
21434 Shannon Court
Cupertino, CA 95014

January 28, 1995

Steven H. Zarit, PhD
Department of Individual and Family Studies
Henderson Human Development Building
Pennsylvania State University
University Park, Pennsylvania 16802

Dear Dr. Zarit:

I am a master's degree student in the nursing program at San Jose State University. One of the requirements for the degree is to complete a research thesis.

The study I proposed for my thesis concerns the identification of activities of daily living, provided to a dependent elder by a caregiver, which may be factors in perceived burden in the caregiver.

I would appreciate your written permission to use the Zarit Burden Interview to determine the level of burden in the caregivers who will participate in the study.

Sincerely,

Laura M. Bour

Laura M. Bour, RN,C BSN

You have my permission to use the Burden Interview for your research.
Steve H Zarit
2/7/95

Appendix L

Request to San Jose State University to Add Site

21434 Shannon Court
Cupertino, CA 95014
(408) 253-2687
November. 10. 1995

Susan Hoagland
San Jose State University
c/o Graduate Studies
One Washington Square
San Jose, CA 95192-0025

Re: Addendum to Protocol: Dependent Elder Care: The Impact on Caregiver Burden

Dear Susan:

Due to the lack of subjects at the Cupertino-Sunnyvale Senior Centers for my study, Dependent Elder Care: The Impact on Caregiver Burden, I would like to add an additional site in which to conduct the study. The location would be the Veterans Administration Medical Center, 795 Willow Road, Menlo Park, CA 94025. The caregivers of clients registered in the Dementia Respite Program would be invited to participate in the study.

Enclosed are copies of the forms from the Stanford University Human Subjects Department and the Veterans Administration Medical Center giving me permission to perform the study. I am also enclosing the revised SJSU Informed Consent form. An additional Informed Consent form, required by the Veterans Administration Medical Center and the Human Subjects Committee at Stanford University, is also enclosed.

Sincerely,

Laura M. Bour

Laura M. Bour, RN,C

Enclosures:

1. Permission form to perform the study, Dependent Elder Care: The Impact on Caregiver Burden, at the Veterans Administration Medical Center (VAMC).
2. Approval by Stanford University Human Subjects Department to perform the study at the VAMC
3. Revised SJSU Informed Consent form.
4. Veterans Administration Medical Center-Stanford University Informed Consent form.

Appendix M

Key for Scoring the Index of Independence in Activities of Daily Living

KEY TO SCORING THE INDEX OF INDEPENDENCE IN ACTIVITIES OF DAILY LIVING

The Index of Independence in Activities of Daily Living is based on an evaluation of the functional independence or dependence of patients in bathing, dressing, going to the toilet, transferring, continence, and feeding. Specific definitions of functional independence and dependence appear below the index.

A. Independent in feeding, continence, transferring, going to the toilet, dressing, and bathing.
B. Independent in all but one of these functions.
C. Independent in all but bathing and one additional function.
D. Independent in all but bathing, dressing, and one additional function.
E. Independent in all but bathing, dressing, going to the toilet, and one additional function.
F. Independent in all but bathing, dressing, going to the toilet, transferring, and one additional function.
G. Dependent in all six functions.

Other: Dependent in at least two functions, but not classifiable as C, D, E, or F.

Definitions

Independence means without supervision, direction, or active personal assistance, except as specifically noted below. This is based on actual status and not on ability. A patient who refuses to perform a function is considered as not performing the function, even though he is deemed able.

BATHING (sponge, shower or tub)

Independent: assistance in only bathing a single part (as back or disabled extremity) or bathes self completely.

Dependent: assistance in bathing more than one part of body; assistance in getting in or out of tub or does not bathe self.

DRESSING

Independent: gets clothes from closets and drawers; puts on clothes, outer garments, braces; manages fasteners; act of tying shoes excluded.

Dependent: does not dress self or remains partly undressed.

GOING TO TOILET

Independent: gets to toilet; gets on and off toilet; arranges clothes; cleans organs of excretion (may manage own bedpan used at night only and may or may not be using mechanical supports).

Dependent: uses bedpan or commode or receives assistance in getting to and using toilet.

TRANSFER

Independent: moves in and out of bed independently and moves in and out of chair independently (may or may not be using mechanical supports.

Dependent: assistance in moving in or out of bed and/or chair; does not perform one or more transfers.

CONTINENCE

Independent: urination and defecation entirely self controlled.

Dependent: partial or total incontinence in urination or defecation; partial or total control by enemas, catheters, or regulated use of urinals and/or bedpans.

FEEDING

Independent: gets food from plate or its equivalent into mouth (precutting of meat and preparation of food, as buttering bread, are excluded from evaluation).

Dependent: assistance in act of feeding (see above); does not eat at all or parenteral feeding.

Appendix N

Letters From Senior Day Center and Primary Researcher to Caregivers for Release of Information

Memo

Date: 04/5/95

To: Caregivers of Participants at CSSDS

From: John T. Timbs

Subject: Research Project

We are often asked to endorse research projects to our client families. We send on to you those which we think have merit. Scientific research can help deepen our understanding of aspects of caregiving or aging; it can dispel myths and suggest surprising conclusions. And, of course, it develops in the researcher an interest in our field.

I am happy to endorse to you this work of Laura Bour, a graduate student at San Jose State. If you wish to participate, please send back the permission slip at the bottom of the attached page. We will then supply her with your name., address and phone number.

Dear Caregiver:

I NEED YOUR HELP! I am inviting you to participate in a study which will investigate if a dependent elder's ability to perform daily personal care activities has an effect on caregiver perceived feelings of burden. If you agree to participate in the study, you will be asked to complete 3 questionnaires that will not take longer than 30 minutes to answer.

Your responses will be coded to the data and maintained in an anonymous manner. The code and individual responses will be destroyed at the end of the study. Data will be presented in an aggregate and individual names will not be associated with the data. You will receive no monetary compensation for your participation. You are free to quit the study at any time.

While there is not likely to be any direct benefit to you, your participation can make a meaningful contribution to increase the understanding of the problems of caregiving. Your signature below will give Cupertino Sunnyvale Senior Day Centers permission to release your name and phone number to the researcher.

Sincerely,

Laura Bour, RN,C
San Jose State University

TEAR HERE

I give permission to Cupertino Sunnyvale Senior Day Centers to give my name, address, and phone number to researcher, Laura Bour

Signed____
Please return this form with your billing statement. Thank you.