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FACTORS INVOLVED IN CAREGIVERS' DECISIONS TO PLACE THE
ELDERLY IN LONG TERM CARE FACILITIES

THE UNIVERSITY OF ARIZONA

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FACTORS INVOLVED IN CAREGIVERS' DECISIONS TO PLACE
THE ELDERLY IN LONG TERM CARE FACILITIES

by

Mary T. Knight

A Thesis Submitted to the Faculty of the
COLLEGE OF NURSING
In Partial Fulfillment of the Requirements
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STATEMENT BY AUTHOR

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APPROVAL BY THESIS DIRECTOR

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December 8, 1983
Date

This thesis is dedicated to my husband, Cecil, whose ongoing love and support assisted me in my role as a caregiver.

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ABSTRACT

The purpose of the study was to identify factors involved in caregivers' decisions to relinquish their roles and thereby admit the elderly to long term care facilities.

The sample consisted of seventeen persons, aged 29 to 79 years. There were thirteen women and four men included in the study. Six of the caregivers were spouses, one was a sibling, and ten were daughters or daughters-in-law.

The findings of the study revealed that the majority of caregivers were of an age where they themselves were having to cope with their own aging process in addition to caring for an elderly relative. The findings indicated that a deterioration in the caregivers' health and a decline in the patients' functional status were the major reasons for placement in a long term care facility.

CHAPTER 1

INTRODUCTION

The provision of long term care for the elderly, which is the fastest growing segment of our population, is an area of concern within our society. As the proportion of elderly persons continues to increase, it can be anticipated that there will be a concomitant increase in the number of disabled elderly. Among the disabled group there is an unknown portion who are being cared for in the home setting by relatives and friends. The ability of these caregivers to sustain their role is a major element in maintaining the disabled elderly within the home setting as opposed to being institutionalized.

The majority of caregivers are family members. They may be an equally aged spouse or sibling, or an elderly son or daughter. The network of caregivers may extend to more distant relatives such as nieces and nephews or, in the case where relatives are unavailable or unwilling to accept the role, it may be assumed by friends or neighbors.

Not all persons are equal to or comfortable in assuming the caregiving role. The reasons for accepting the role can be as varied as the persons fulfilling the role. Quite often the caregiver may be a devoted spouse or child

who assumes the role as a natural progress of a relationship. At other times the reason may stem from a feeling of responsibility or duty to a family member or friend. The dislike for institutionalization, or the prohibitive cost of such care, may be an important factor in one's decision to assume the role. For others, the decision may be based on an unawareness or unavailability of alternatives to the present situation.

Caregiving demands often cause shifts in roles and role relationships. A wife who has been financially and emotionally dependent upon her husband may unexpectedly be thrust into a decision making role beyond that with which she is familiar. A husband may have to assume responsibility for household duties previously attended by his spouse. The tasks associated with caregiving may be unfamiliar and frightening to the caregiver. Social isolation due to caregiving demands may be inherent in the situation. Social support may be limited or non-existent. Thus, the need to be able to communicate fears and frustrations and to receive validation for what one is doing may not be forthcoming.

A daughter or daughter-in-law may suddenly have the addition of an aged parent in her home. Such situations can lead to overcrowding, lack of privacy, and economic hardships. A grandchild may be asked to give up his or her

room. A family room or other gathering area may be transformed into a bedroom. Friends and neighbors may no longer be invited into the home due to lack of space or embarrassing behaviors exhibited by the person receiving care. A wife may have to cease employment in order to assume the caregiving role and/or a husband may have to take on a second job in order to meet expenses incurred in the care of the disabled elder. The continuous tension associated with the number and difficulties of problems can lead to high stress in the family situation. Role conflict may occur wherein the willingness to care may be at a cost to other family members whose needs go unmet.

Physical stamina is also necessary to perform the tasks of caregiving. The physical needs of the patient may vary from minimal assistance with the activities of daily living to total care for the incontinent, confused, wanderer. The spouse who assumes the caregiving role is usually near the age of the individual receiving the care. Thus, they themselves may have reduced physical reserves and coping abilities. Many of the children of persons in their eighties and nineties have experienced some of the chronic illnesses associated with their own aging. As the condition of the patient deteriorates, there is an increase in the physical needs and psychological demands placed on the caregiver. Unlike institutional situations, where care is

given on a shift basis, the caregiver may be the only other person in the household or the only one delegated as caregiver and, therefore, subjected to twenty-four hour periods of unrelenting service. Such demands can lead to an excessive burden, resulting in health problems for the caregiver. While some caregivers are able to continue in this role for years, the ability of others to sustain this role may prove impossible.

Purpose of the Study

The purpose of this study is to identify factors involved in caregivers' decisions to relinquish their roles and thereby place the elderly in long term care institutions. The researcher is interested in who functioned as caregivers and what types of supports they received from various sources. The functional status of the patients at the time of admission to the long term care facility will also be considered. The researcher was further interested in caregivers' perceptions of what supports could have assisted them in maintaining their roles.

Statement of the Problem

The study is designed to answer the following questions:

1. What was the functional status of the patient at the time of institutionalization as identified by the caregiver?

2. What alterations in the caregiver's lifestyle was necessitated by the caregiving role?
3. What support services were utilized prior to the admission of the elderly person to the long term care facility?
4. What types of support services would caregivers liked to have had to assist them in their role and how often would they have wanted services to be available to them?

Significance of the Problem

Nurses are continuously interacting with elderly clients and their caregivers. Yet there is a noticeable dearth of information pertaining to the non-professional caregiver within the nursing literature. In order for nurses to be able to assist the caregiver in maintaining his or her role they must be aware of the stresses associated with the demands of caregiving. Intrapersonal and interpersonal ways of dealing with these stresses must be identified and utilized.

Caregivers often have feelings of frustration and defeat when they are expected to perform tasks and procedures with which they are not familiar. The conveniences of an institutional setting are not available in a home. Equipment may have to be improvised, assistance in transferring someone from a bed to a chair may not be available, and persons to discuss concerns with may not exist. Many of

the disabled elderly are unable to perform such basic tasks as bathing, feeding, and toileting. These inabilities may stem from physical decrements and/or mental deterioration. Without assistance in meeting these needs the quality of life would deteriorate and the quantity of life would be threatened. It is the availability and the willingness of a caregiver to assist in meeting these needs which is often the principal factor in delaying, if not preventing, the institutionalization of the disabled elderly.

The demands placed on caregivers may be so overwhelming that everything else becomes secondary to the caregiving needs they perform. The ability to choose how one's day will be spent is no longer possible. Social contacts may already be reduced due to retirement, loss through death, and relocation. The added restrictions placed on outside activities result in decreased social interaction. An adult child who is facing his or her own problems of aging may be unable to cope with the ongoing physical and/or mental deterioration of an aged parent. The necessity for adjustments in the post retirement plans of a spouse or an adult child may lead to feelings of resentment toward the patient and other family members. Lack of time to attend to one's own needs and sleep deprivation, with resultant loss of identity and fatigue, are common occurrences. The inability of the caregivers to cope with these changes may

affect their psychological, social, and physical well-being. Support systems have a major impact on a caregiver's ability to cope with the stresses and resultant changes in their lifestyle. The study will assist nurses and other health care professionals in understanding what supports were utilized by caregivers prior to placing the disabled elderly person in a long term care facility and what supports the caregivers felt would have been beneficial.

Conceptual Framework

Social support is generally viewed as a buffer system which aids an individual in coping with stress (Lin et al., 1979). Lindsey and Hughes (1981) noted that the home care of the elderly can become an intolerable stress. Figure 1 is a diagram of the conceptual framework for the study. The focus of the framework is how social support can act as a mediating variable which can assist the caregiver in sustaining his or her role.

Unger and Powell (1980) noted that the emotional and material support received from informal and formal sources play a critical role in facilitating an individual's adaptation to stress. Snow and Gordon (1980, p. 464) also supported this view. The authors stated that, "Aspects of social support are seen as critical to functioning and adaptation of the individual especially in times of crisis when supportive relationships can mediate the effects of

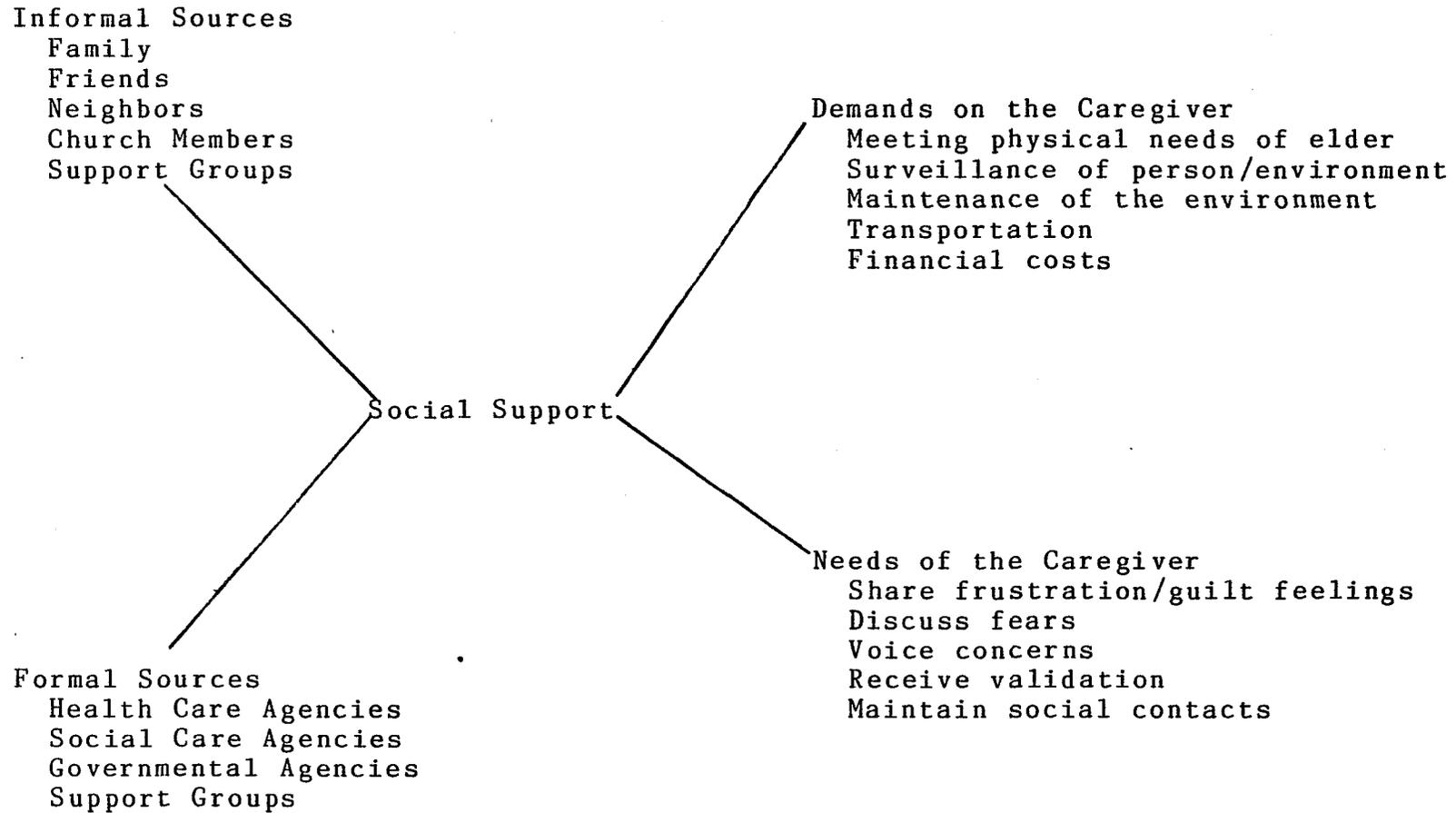


Figure 1. Diagramatic Representation of Social Support as an Influence in the Life of the Caregiver

stress." The informal sources of social support include family, friends, neighbors, and church members. Health care agencies, social care agencies, and governmental agencies are considered formal sources. Support groups may develop as either a formal or informal type of resource.

The assistance received from the various sources can be in the form of instrumental support, emotional or social support, and referral and information (Unger and Powell, 1980). Gelein (1980) noted that support systems help an individual to mobilize psychological resources, share tasks, and provide supplies of money, material, tools, and skills. Instrumental aid which provides goods or services can reduce the demands which have been placed on the caregiver. Lindsey and Hughes (1981) cited the need for periodic and temporary relief from the long term continuous responsibility of caring for an aged member as one of the major areas identified by caregivers of patients with psychiatric illnesses. Two serious impediments to the long term care of these patients were the constant nature of required supervision and the amount of physical care required. Archbold (1980) also noted that the ability to have definite periods of relief from responsibility was a desire of most caregivers. An important factor in maintaining one's role was dependent upon the degree to which the caregiver could obtain meaningful role relief (Goldstein, Regnery, and Wellin, 1981).

The demands on the caregiver include meeting the physical needs of the patient, surveillance of the patient and the environment, maintenance of the environment, transportation, and financial costs. Family members can assist in meeting the physical needs of the patient by performing such tasks as bathing and feeding. Laundry, shopping, and household chores may be readily assumed by neighbors and friends. Sitting services may be available through church members. Some family members may assist with transportation needs and/or be willing to take the patient to their home for a weekend. The provision of supplies and money may be obtained through informal sources. Formal support sources would include such services as nursing, home health aides, homemaker assistance, day care, respite care, transportation, mobile meals, and Medicare reimbursement for supplies and services.

Not all caregivers need or want the same types and amounts of support. The functional and mental status of the patient and the health status of the caregiver will be major determinants of the types and amounts of support deemed necessary by the caregiver. Minkler (1981) stated that social networks helped increase one's coping response to stress and thus helped "short circuit" the illness response. Lin, et al. (1979) also supported this view. The authors stated that there is a general assumption that a negative relationship exists between social support and the occurrence of

illness. That is, the greater the amount of social support one receives, the less likely one will become ill. In a report written by Unger and Powell (1980, p. 567) it was noted that "the preference for informal as opposed to formal sources of aid still appear prevalent." This may, in part, be due to the financial costs involved in procuring such services.

Social-emotional aid provides for meeting the needs of the caregiver through listening, communicating, and sharing of information. Support is necessary to assist the individual to cope with lifestyle changes and stresses which result from the caregiving role. Brandt and Weinert (1981) indicated that a socially supportive environment facilitated a positive response to stressful life events. In a study of caregivers of patients with senile dementia, Zarit, Reeve, and Bach-Peterson (1980) noted that an approach that includes support to the caregiver as well as attention to modifiable aspects of the patient's behavior may contribute the most to making the situation more manageable. Other authors (Aronson and Lipkowitz, 1981; Crossman, London, and Barry, 1981; Norbeck, 1981) also addressed the need to provide support to the caregiver.

The caregiver must be able to share feelings of frustration and guilt. Guilt often arises due to anger directed toward the patient when the caregiver is having difficulty coping with all of the demands placed upon him or

her (Archbold, 1980; Aronson and Lipkowitz, 1981; Barnes et al., 1981; Rabins, Mace, and Lucas, 1982). The caregiver has the need to feel that what he or she is doing is worthwhile. Social-emotional support to help meet the needs of the caregiver can come from both the informal and formal networks. Barnes et al. (1981) reported on a support group for the spouses of patients with Alzheimer's disease. The benefits derived from participating in the group included an increased understanding of the disease entity resulting in more realistic expectations towards the patient. A resultant decrease in anger and frustration was also noted. The sharing of feelings was also cited as being beneficial. The spouses felt that others understood their plight and could communicate empathy. Family and friends who visit can provide meaningful contact with the outside world for those who are socially isolated. Being a confidant to the caregivers allows them to voice their concerns. Formal agencies can provide confirmation regarding the value of the care being given. Fears can be alleviated through education. Assisting caregivers to recognize what supports are available and how they can be utilized can help to alleviate distress.

Aronson and Lipkowitz (1981, p. 570) stated, "when and whether the patient requires institutionalization depends more on the coping skills of the spouse than on the condition of the patient. Ongoing support can reduce the demands and lead to increased coping abilities of the

caregiver. This, in turn, can assist the caregiver in maintaining his or her role and thereby delaying or preventing the institutionalization of the disabled elderly.

Definitions

For the purposes of this study, the following definitions were used:

1. Functional Status: A patient's physical and mental ability to carry out the activities of daily living as measured by an adaptation of Katz's Index of Independence in Activities of Daily Living.
2. Caregiver: An individual who assumes responsibility for the care which another individual is incapable of performing for him or herself.
3. Alterations in Lifestyle: Those changes affecting the physical, social, psychological, and environmental status of an individual which occurred during the time he or she functioned as a caregiver.
4. Social Support: Those persons and/or agencies which assisted the caregiver through the provision of goods and services or through listening, communicating, and sharing of information.

CHAPTER 2

SELECTED REVIEW OF LITERATURE

This chapter includes a selected review of the literature pertaining to the need for social support to assist in alleviating the burden on caregivers. Certain factors have been suggested as contributing to the burden. Among these are caregiver's health and psychological well-being, social isolation, conflict occurring between the patient and the caregiver or between the caregiver and other family members, financial problems, and the functional status of the patient. Each of these areas will be identified and explored in this chapter.

Caregivers' Health

Many caregivers of the disabled elderly are themselves elderly or approaching their later years. While aging itself is not synonymous with failing health, there is a general acceptance that decreased energy levels and the onset of chronic ailments are more prevalent as one ages. The changes of aging in addition to the changes generated by the caregiving role can affect the health of the caregiver. Rahe and Arthur (1978) noted that a significant relationship was shown between an individual's recent life changes and

the development of illness. The authors further stated that the psychological and physiological efforts necessary for an individual to adjust to severe changes appear to predispose the person toward the development of illness.

Middle aged and aging women are the principal caregivers to the aged (Brody, 1981; Getzel, 1981; Crossman, London, and Barry, 1981; Treas, 1977). In a survey of 224 patients who resided with a caregiver, it was noted that more than 60 percent of the caregivers were women and close to 60 percent were of the same generation as the patient. The median age of the patients was 77 years (Goldstein, Regnery, and Wellin, 1981). "The emotional strain and the physical demands of caregiving are superimposed on the stresses the older woman is already experiencing as she attempts to cope with her own aging process with all its attendant changes" (Crossman, London, and Barry, 1981, p. 464).

In studies reported by Davis (1980) and Goldstein, Regnery, and Wellin (1981), it was stressed that the health status of the caregiver was one of the major factors considered in the decision to maintain a disabled patient at home. Bergmann, et al. (1978) found that the physical health of caregivers was affected in one third of those families residing with an elderly patient who had dementia. Sainsbury and Grad de Alarcon (1970) studied specific effects on families of patients aged 65 and over at the time

of referral for psychiatric evaluation. They noted that 58 percent of the closest relatives cited physical health problems. Stress and fatigue associated with the sustained caregiving of the impaired elderly have been implicated in the mental and physical symptomatology of caregivers (Dunlop, 1980). Golodetz, et al. (1969) conducted an exploratory study of the care of chronic illness. Seventy-five percent of the patients were 60 years or older. They found significant illness in 31 of the 59 caregivers. The illnesses were either chronic illnesses requiring ongoing medical attention, long established deformities, or a type of psychosis. In a study of six post-stroke elderly, Archbold (1980) found that 50 percent of the families had encountered at least one major health problem since assuming the caregiver role. The author further stated, "Caregivers deprived themselves of needed medical care and rest periods because of their responsibilities to the parent" (p. 83).

Psychological Well-Being

All individuals have personal interests and needs. Difficulties arise when an individual is unable to attain or fulfill these interests and needs such as when assuming the role of caregiver. Archbold (1980) noted that activities meaningful to the caregiver were given up in deference to the care of the patient. Morycz (1980, p. 20) stated, "Individual interests and personal needs became submerged

and overcome by the needs and demands of the patient." One of the major problems cited by caregivers of patients with Alzheimer's disease was the time and effort required to meet the needs of the patient. The time involved was so encompassing and continuous that caregivers often lost sight of their own personal needs and interests (Barnes, et al., 1981).

Caregivers of patients with brain altering conditions were found to be particularly vulnerable to stress and depression (Morycz, 1980; Barnes, et al., 1981; Lezak, 1978). In an interview conducted with 55 caregivers of patients with dementia, the authors noted that 88 percent of the caregivers "reported feeling angry, sad, depressed or tired most of the time" (Rabins, Mace, and Lucas, 1982, p. 333). Personal responsibility or inappropriate guilt about behavioral problems was expressed by many spouses. Guilt due to the patient's continual deterioration despite the caregiver's best efforts to provide care was also noted. Many spouses, frightened by episodes of belligerence, were reluctant to impose limits on inappropriate behavior (Barnes, et al., 1981).

Loss of a spouse "through illness" can create a severe crisis in the ability to fulfill interpersonal needs. At times the life of the caregiving spouse can be equated to widowhood. There is no partner with whom one can share. A spouse's sexual and affectional needs are frustrated

(Morycz, 1980). "The spouse cannot mourn decently" (Lezak, 1978, p. 593). Barnes, et al. (1981) wrote of the fact that many spouses are living with a person whose appearance may be the same but whose mind is no longer similar to the person they married. Despair often results from the hopelessness of the situation (Kimsey, Tarbox, and Bragg, 1981).

Social Isolation

Life events may be viewed as "decidedly more burdensome" by individuals who find themselves socially isolated (Rahe and Arthur, 1978, p. 8). In a study of older women caring for disabled spouses, the authors noted that caregivers often experienced feelings of isolation and loneliness (Crossman, London, and Barry, 1981). Golodetz, et al. (1969) found that the caregiver was the only other adult in 70 percent of the households they studied. These findings were similar to Sanford's (1973), in which the author studied 50 geriatric admissions of families who could no longer cope with caring for the patient at home. As Golodetz, et al. (1969, p. 388) noted, "our home-care households were small, isolated, and preoccupied with the care of illness."

Archbold (1980, p. 80) stated, "Social isolation was a universal problem, not only among the ill persons, but

also with their caregivers." The author noted that the isolation was due to such factors as loss of interest on the part of friends, time constraints, and transportation problems. Morycz (1980) and Barnes, et al. (1981) also attested to social isolation having an impact upon caregivers' burdens. Fear and/or embarrassment due to a patient becoming lost or upset in unfamiliar surroundings was cited by many spouses of patients with Alzheimer's disease as a reason to curtail outside activities. The spouses also indicated that they felt isolated and unsupported by the community at large (Barnes, et al., 1981). In a study of role fatigue among caregivers, the authors (Goldstein, Regnery, and Wellin, 1981) cited confinement within the home and restriction on outside activities as the most frequently mentioned problems. The authors noted that caregivers became as homebound as the patients. Robinson and Thurnker (1979) studied the caregiving role of older children for their aged parents. They noted that the actual instrumental care necessitated by the parents was not viewed to be as burdensome as the routines and confinements which resulted from their parents' needs.

Conflict

The changes that occur to the caregiver due to the increased dependency of the patient can result in alterations in interactions, which can lead to increased tension

within the household. Tension, in turn, can result in conflict. Feelings of resentment and anger were voiced by spouses of patients with Alzheimer's disease. Wishes and fantasies regarding the patient's early death were also expressed (Barnes, et al., 1981). Aronson and Lipkowitz (1981) noted that inadequate information about a spouse with a dementing condition in conjunction with the bizarreness of the patient's behavior often reawakened old conflicts in the relationship. Forty-four percent of families of patients with a dementing illness cited excessive demands on their attention and companionship as contributing to the burden of caregiving (Bergmann, et al., 1978). In a study of younger patients with chronic illnesses, the authors noted that 56 percent of the spouses scored an increase in role tension. The authors indicated that this was due to interpersonal conflict and frustration (Klein, Dean, and Bogdonoff, 1967).

The care of aged parents is one of the competing responsibilities confronting mature women. The interests of husbands and children must be balanced against those of aging kin (Treas, 1977). For those couples whose children have grown and whose long awaited freedom has arrived, the responsibility of caring for an aged parent can lead to feelings of being overwhelmed (Olsen and Cahn, 1980). The time and energy required to care for an aged parent can

generate conflict with previous goals. Brody (1981), in her study of middle aged women as caregivers, noted that the competing demands may be between caregiving responsibilities and unfulfilled expectations of what the retirement years would bring. In another study by the same author, she stated, "the adult children's own problems of aging have become more apparent and more frequent as precipitants or as major contributing factors in the family disturbance leading to the need for placement of the parent" (Brody, 1966, p. 202).

Criticism from non-caregiving relatives has been cited by various authors (Morycz, 1980; Lezak, 1978; Rabins, Mace, and Lucas, 1982). In a study entitled "The Impact of Dementia on the Family," 31, or 56 percent, of the caregivers who were interviewed reported receiving criticism and/or less than adequate assistance from other family members (Rabins, Mace, and Lucas, 1982). Lezak (1978) noted that relatives who continued to show interest in the patients' welfare without assuming any responsibility for their care were inclined to be critical of the caregiver. They often perceived the caregiver as too protective or uncaring. Getzel (1981) writes about troubled family relationships having an influence upon the caregiving potential. The author states, "Older persons may credit noncaregiving relatives with affection and regard, while

denying importance to the actual help provided by the primary caregiver" (p. 208).

Financial Problems

Caring for a disabled elderly person may be of a short duration or it may continue for years. The added expenses, whether they occur from cost of materials and services or from a loss of income due to the caregiving role, can increase the burden upon the caregiver. Many of the patients being cared for in the home setting do not qualify for insurance reimbursement due to the chronicity of their problems. Barnes, et al. (1981) noted that the cost of home care or respite care for patients with Alzheimer's disease was prohibitive for those on fixed incomes. Financial burden was listed as one of the environmental burdens affecting the families of patients with senile dementia (Morycz, 1980). Strained finances, resulting from added expenses, were also cited by Archbold (1980) and Goldstein, Regnery, and Wellin (1981). In two studies concerning abuse of the elderly, it was noted that the financial and emotional goals of middle aged children can be frustrated by requirements necessary to care for an aged parent (Steuer and Austin, 1980; Kimsey, Tarbox, and Bragg, 1981).

In a study of the life satisfaction scores of wives of elderly disabled men, the authors noted that wives with high life satisfaction scores were better off financially.

The authors further stated that, "Low income obviously reduced access to means that might make living with a handicapped person more bearable" (Fengler and Goodrich, 1979, p. 179). Cost of care was cited as a significant factor in wives' decisions to avoid or delay institutionalization (Crossman, London, and Barry, 1981). The authors suggested that fear of an impoverished existence for themselves following the death of their spouse may have been a major reason for the reluctance of these caregivers to seek institutionalization.

Functional Status

The emotional and physical capacities of the caregiver may be strained by the ever increasing demands placed upon them. Most long term chronically disabled elderly persons do not tend to have an overall improvement in their health status; rather, their dependency needs tend to increase with time. In a study of elderly patients with dementia admitted to a psychiatric day hospital, Bergmann, et al. (1978) noted that prior to admission 33 percent of the patients required constant nursing care. The authors indicated that the physical breakdown of the health of the patients may have been a major precipitating factor in their spouses' decisions to seek institutional care. In a paper addressing the need for home care, the author (Dunlop, 1980) noted that when personal care needs become continuous or

nursing care is required on a daily basis, most families will seek institutional care. Swartz (1982) writes that the decision regarding community versus institutional care is often dependent upon the degree of combined physical and mental disability of the patient.

Many authors have cited sleep disturbance with a resultant denial of rest for the caregiver as contributing to the excessive burden (Morycz, 1980; Barnes, et al., 1981; Rabins, Mace, and Lucas, 1982; Sanford, 1973; Smallegan, 1981; Crossman, London, and Barry, 1981; Zarit, Reeve, and Bach-Peterson, 1980). Day-night reversal was noted to be common among patients with Alzheimer's disease. Such reversal left the caregiver with feelings of exhaustion and the inability to cope (Barnes, et al., 1981). In a study by Sanford (1973), 62 percent of caregivers cited sleep disturbances due to night wandering, irrational shouting, and patients' inability to get on and off the commode by themselves. Eighty-four percent of those reporting said it had become an intolerable situation.

Urinary incontinence has been suggested to be one of the major precipitants for seeking institutional care (Freed, 1981; Maney, 1980; Demmerle and Bartol, 1980; Vetter, Jones, and Victor, 1981). Demmerle and Bartol (1980) reported that families of 20 institutionalized patients with dementia cited incontinence as a principal factor in the decision to place their relatives in long term

care facilities. Vetter, Jones, and Victor (1981) have estimated that, "incontinence is a contributory factor in up to one fifth of geriatric admissions to hospitals" (p. 1275). Rabins, Mace, and Lucas (1982) reported that 62 percent of caregivers interviewed cited urinary incontinence as a most serious problem. Interestingly, in Sanford's (1973) study, urinary incontinence was frequently reported but 81 percent of those reporting felt they could tolerate the situation. This may be due to the availability of an incontinence laundry service in England where the study was done.

The patient's level of immobility has also been found to affect the tolerance level of the caregiver. Sanford (1973) reported that the patient's inability to get in and out of bed and on and off the commode was viewed as less tolerable than the patient's ability to ambulate. The author believes this is due to the physically taxing nature of such moves. Smallegan (1981) noted that difficulty in ambulation was the most predominate problem in 19 admissions to long term care facilities. Twelve of the patients were confined to bed or to wheelchairs. These findings support Grad and Sainsbury's (1963) belief that bedfast patients have a significant effect upon the caregiver's burden.

Among those caring for patients with dementia, aggression and physical and verbal abuse were cited as contributing to the burden (Morycz, 1980; Rabins, Mace, and Lucas, 1982; Grad and Sainsbury, 1963). Physical violence

was reported as a serious problem by 75 percent of caregivers (Rabins, Mace, and Lucas, 1982). The five symptoms associated with severe burden as reported by Grad and Sainsbury (1963) were aggression, delusions, hallucinations, confusion, and the inability to care for one's self.

Social Support

Families have been described as "responsible caregiving agents who provide substantial physical, emotional, social, and economic support to their chronically ill elderly relatives" (Brody, Poulshock, and Masciocchi, 1978, p. 557). It has been estimated that one third of all community based elderly require some degree of long term service. Approximately 80 percent of all care of the elderly residing in the community is provided by the family (Brody et al., 1978; Minkler, 1981). However, as Eggert et al. (1977) noted, there is an erosion, over time, of the willingness and capacity of caregivers to continue if their burdens are not shared. Johnson and Bursk (1977) stated that time away from responsibilities associated with caring for an aged parent was as important for an adult child as for a parent with preschool children.

Social support has been defined as "the degree to which a person's basic social needs are gratified through interactions with others" (Thoits, 1982, p. 147). Unger and Powell (1980) cited instrumental support, emotional or

social support, and referral and information as the three types of aid provided through one's social network.

Crossman, London, and Barry (1981) reported that while some caregivers continue to derive support from the caregiver-patient relationship that continues to exist, others who are caring for patients with brain injuries can no longer rely on the companionship and confidant relationship that previously existed. Zarit, Reever, and Bach-Peterson (1980) noted an inverse relationship between the reported level of burden and the social supports available to the caregivers of patients with dementia.

Social support leads the caregiver to believe that others recognize the enormity of their caregiving tasks (Crossman, London, and Barry, 1981). Caregiving wives who reported high life satisfaction scores received social support, in both an expressive and instrumental nature, from family, friends, and neighbors (Fengler and Goodrich, 1979). The family may be the most important source of social support, particularly in later life when the non-family network of support declines (Lindsey and Hughes, 1981). Norbeck (1981) notes that with increasing age there is a loss of opportunities for gaining new supports, and a further loss of support is realized through the death of family and friends. The author further stated that while support may be available during an acute crisis, it does not tend to persist in the transition from an acute to a chronic status.

Thoits (1982) also noted that certain events can produce alterations in a social support system. The long term commitment to care for an elderly disabled person can result in an augmentation or a lessening of one's social support system.

Health professionals as well as family and friends can be considered as major sources of social support for caregivers (Fuller and Karlson, 1981). It is essential that formal care providers understand the role of the family in the care of the elderly and that they foster active participation of family members (Olsen and Cahn, 1980). In addition, a health professional can provide emotional support and act as a confidant. Those services provided by formal support sources must be designed to meet the needs of the caregiver as well as the needs of the disabled elderly. Getzel (1981) noted that the aim of agency services should be to relieve the stress and burden of the caregiver who is deeply enmeshed in an emotionally demanding role.

Summary

This review of the literature has presented a summary of the writings of many authors in relation to various aspects which have been suggested as contributing to the burden of caregiving. Studies substantiating the authors' viewpoints have been presented within each area of concern.

The role of social support as having an influence upon the burden of the caregiver has also been explored.

CHAPTER 3

METHODOLOGY OF THE STUDY

This chapter includes a discussion of the design of the study, the setting in which it occurred, the sample and criteria for inclusion, the method of data collection, and the questionnaire used as the measurement tool.

Design of the Study

A descriptive study was designed to answer the following questions: What was the functional status of the patient at the time of institutionalization? What lifestyle changes occurred in the life of the caregiver during the time he or she was caring for the patient? What support services were utilized by the caregiver? What types and amounts of support services would the caregiver have liked to have had to assist them during the period of caring for the patient?

The Setting

The setting for the study was a large metropolitan area located in the southwestern United States. Arrangements to obtain subjects were made with Directors of Nursing and/or the Administrators at various long term care

facilities. Only those long term care facilities willing to allow the researcher to contact all caregivers who met the criteria were considered for inclusion in the study.

The Sample

The sample included seventeen caregivers who met the following criteria:

1. Able to read and speak English.
2. Resided in the same household as the patient.
3. Cared for the patient for at least one week prior to institutionalization.
4. Cared for a person who was 60 years of age or older.
5. Cared for a person who was admitted to a long term care facility from a home setting.
6. Cared for a person who had been institutionalized no less than one week nor longer than six months.

Method of Data Collection

Representatives of eight long term care facilities were contacted and the study explained to them. The representatives included five administrators, two directors of nursing service, and one director of social services. All initially agreed to participate in the study by referral of caregivers who met the criteria. However, two administrators withdrew without having participated citing time constraints involved in identifying which caregivers met the criteria.

Caregivers were contacted by a representative of the facility to obtain permission to release their names to the investigator. This contact was established by the social workers at five of the facilities and the administrator of the sixth facility. Two of the twenty-three persons who were initially contacted refused to have their names released.

After the names were received by the investigator a letter (Appendix A) was sent to all potential subjects. The potential subjects were then contacted by phone to ascertain their willingness to participate in the study. A review of the criteria revealed that two of the twenty-one persons contacted did not meet the requirements for inclusion in the study. Two caregivers also refused to participate in the study when contacted by the investigator. The spouse of one of the caregivers refusing to participate had expired since the original request had been made.

A mutually agreed upon time was established to conduct the interview for those willing to participate in the study. Sixteen of the interviews were conducted in the subjects' homes. One subject chose to meet the researcher at the long term care facility. A private, quiet area was provided by the facility for the duration of the interview.

Each subject was asked to read the Disclaimer Statement (Appendix B) prior to answering the questionnaire. This study was approved as exempt from University review by

the College of Nursing Ethical Review Sub-committee of the Research Committee, and the Director of Research (Appendix C). During the interview each subject was given a 5x8 card listing the possible responses to the questions asked. The researcher was present during the interview to answer any questions the subject had. Approximately forty-five minutes to one hour was required to complete the questionnaire.

The Measurement Instrument

A three-part questionnaire was developed by the researcher to obtain data from the caregivers. The responses to the questionnaire were collected during a personal interview with the subjects. The development of the questionnaire was based upon the review of the literature, the researcher's personal experience as a caregiver, and the researcher's professional experiences of working with the caregivers of the elderly disabled population.

Part I (Appendix D) contains eighteen questions and was designed to obtain information about the person who received care. The first five questions pertain to demographic information. They include questions as to the patient's age and sex. The length of time the patient was cared for and by whom, and the length of time since the patient was admitted to the long term care facility was obtained.

The next twelve questions, numbers six through seventeen, reflect the caregiver's perception of the patient's physical and mental abilities at the time of institutionalization. The ten functional status items included in the questionnaire were adapted from those developed by Katz, et al. (1974). The authors had included fourteen items in their classification scheme. The responses to the five physical functional items (numbers six through ten) were given a value ranging from one to four to determine the degree of assistance that the patient required from the caregiver. One indicates no assistance, two indicates minimal assistance, three indicates maximum assistance, and four indicates total assistance. The possible range of scores for the five functional status items associated with the activities of daily living was from five to twenty. Two questions, numbers eleven and twelve, relating to urinary and bowel incontinence, were also included. The next three questions in Part I pertain to the patient's communication ability, orientation, and behavioral patterns. Frequency of selection and percentages were used in the analysis of data.

The final three questions, numbers sixteen through eighteen, were designed by the researcher. The purpose was to obtain further information about the patient's behavior and sleep patterns. Information regarding the amount of

time per day that the patient required assistance was also obtained.

Part II (Appendix E) contains twenty-eight questions. The first sixteen questions, numbers nineteen through thirty-four, obtain information about the caregiver. Questions germane to the subject include such areas as health, sleep deprivation, free time, constraints on mobility, social interactions, and feelings which the caregiver experienced during the time he or she was caring for the patient.

The remaining twelve questions, numbers thirty-five through forty-six, elicit information pertaining to the setting in which the care took place and the costs incurred. Questions referring to the setting establish where the care took place and the numbers of other persons present in the household. Tension resulting from the situation and the reactions of others toward the caregiver were identified. The subject's income and financial costs as a result of caring for the patient was obtained. A single question relating to changes in vacation/retirement plans secondary to caring for the patient was also included. Frequency distribution of responses and percentages were used in the analysis of data.

Part III (Appendix F) of the questionnaire contains thirty-one questions. The questions obtain information about social supports which assisted in caring for the

patient and relieving the caregiver of other responsibilities. The types of assistance received and the persons or agencies providing the assistance were identified. Certain questions attempt to elicit the caregiver's feelings about the benefits of having received such assistance. The frequency with which the caregiver would have liked to have had such supports and persons the caregiver would have liked to have had provide the support was also obtained. The presence or absence of a confidant was identified. The analysis of data was based on frequency distribution and percentages of the selected responses.

The last two questions submitted to the caregiver were open-ended questions. The purpose was to elicit the caregiver's response regarding the deciding factor or factors in making the decision to admit the patient to the long term care facility and to elicit his or her response regarding guilt feelings associated with the decision to place the elderly person in a long term care facility. The responses to the open-ended questions were categorized and reported according to frequency distribution of the specific categories.

The measurement tool was pre-tested on four subjects to ascertain clarity, ease of administration, and to discover any ambiguous statements. No changes were deemed

necessary. The data obtained in the pre-test is not included in the final analysis.

Summary

The instrument used to collect data was a three-part questionnaire developed by the researcher. The questionnaire was designed to elicit responses which would answer the questions set forth in the purpose of the study. Data analysis is based on frequency distribution and percentages of the specific responses.

CHAPTER 4

FINDINGS OF THE STUDY

The sample for this study consisted of seventeen caregivers who had cared for an individual 60 years of age or older in a home setting. All of the individuals cared for had been admitted to a long term care facility at the time that the study was carried out. This chapter contains a description of the characteristics of the persons who were cared for, a description of the characteristics of the persons who functioned as caregivers, and an analysis of the data collected. The analyses and findings relating to support systems will also be described.

Characteristics of the Patient Population

Demographic Characteristics

The distribution of the patients by age and sex is presented in Table 1. The patient population consisted of four males (24 percent) and thirteen females (76 percent). The mean age of patients was 81.6 years and the median 83 years. The age range was from 61 to 93 years. As noted in the table, ten (59 percent) of the patients were 80 years of age or older.

Table 1. Frequency Distribution of Patients by Age and Sex

| Age in Years | Sex | | | | Total | |
|--------------|-----------|------|-------------|------|-------|-------|
| | Male # | % | Female # | % | # | % |
| 60 - 69 | 0 | 0.0 | 1 | 5.9 | 1 | 5.9 |
| 70 - 79 | 2 | 11.8 | 4 | 23.5 | 6 | 35.3 |
| 80 - 89 | 1 | 5.9 | 5 | 29.4 | 6 | 35.3 |
| 90 - 99 | 1 | 5.9 | 3 | 17.6 | 4 | 23.5 |
| Total | 4 | 23.6 | 13 | 76.4 | 17 | 100.0 |

mean = 81.6 years
 median = 83 years

Length of Caring and Length Since Admission

The mean length of time for which the individuals had been cared for in the home setting was 187.05 weeks (3.6 years) with a median of 156 weeks (3 years). The range was from 3 weeks to 572 weeks (11 years). The range since admission to a long term care facility was 3 weeks to 24 weeks with a mean of 12.94 weeks.

Functional Status of the Patients

The investigator was interested in determining the functional status of the patients as perceived by the caregivers. Each caregiver was asked to respond to twelve questions relating to the physical and mental status of the patient at the time of admission to the long term care facility. Five of the questions refer to the type of assistance required by the patient in performing the activities of daily living. The responses are listed in Table 2. Weights of one point for no assistance to four points for total assistance were assigned to each of the five categories with a resultant possible score of 5 to 20. The actual range of scores was 5 to 18. One patient received a score of 5 while six patients each received scores between 6 to 10 and 11 to 15. Four patients received scores between 16 to 20. The mean score for activities of daily living was 11.4 with a median of 11.25.

Table 2. Subjects' Responses* to Statements Regarding Assistance Required in the Patients' Activities of Daily Living

| Subject | Activities of Daily Living | | | | | Total Score |
|---------|----------------------------|----------|---------|--------------|--------|-------------|
| | Bathing | Dressing | Walking | Transferring | Eating | |
| 1 | 4 | 4 | 4 | 3 | 3 | 18 |
| 2 | 3 | 3 | 3 | 2 | 2 | 13 |
| 3 | 4 | 3 | 1 | 2 | 2 | 12 |
| 4 | 2 | 1 | 1 | 1 | 1 | 6 |
| 5 | 2 | 3 | 1 | 1 | 1 | 8 |
| 6 | 3 | 3 | 1 | 1 | 2 | 10 |
| 7 | 1 | 1 | 1 | 1 | 1 | 5 |
| 8 | 4 | 4 | 3 | 3 | 3 | 17 |
| 9 | 3 | 3 | 3 | 3 | 3 | 15 |
| 10 | 4 | 4 | 3 | 3 | 4 | 18 |
| 11 | 3 | 1 | 2 | 1 | 1 | 8 |
| 12 | 1 | 1 | 2 | 1 | 1 | 6 |
| 13 | 3 | 3 | 4 | 3 | 3 | 16 |
| 14 | 3 | 3 | 3 | 2 | 3 | 14 |
| 15 | 2 | 3 | 2 | 1 | 3 | 11 |
| 16 | 1 | 1 | 2 | 1 | 1 | 6 |
| 17 | 2 | 3 | 3 | 2 | 1 | 11 |

*
 1 = no assistance
 2 = minimal assistance
 3 = maximum assistance
 4 = total assistance

mean = 11.4
 median = 11.25

The incidence of urinary and bowel incontinence was also of interest to the investigator. As shown in Table 3 only one patient was noted to be totally incontinent of urine. Five persons (29 percent) were listed as having occasional mishaps while six persons (35 percent) had frequent mishaps. Occasional mishaps were described as occurring once or twice a week. Frequent mishaps were described as occurring more frequently but not consistently. Nine persons (56 percent) were reported to have complete control of bowel elimination. Occasional mishaps were noted for five persons (31 percent) and frequent mishaps were reported for two persons (13 percent). One patient was not included in bowel continence due to having a colostomy which was controlled by irrigation.

The remaining five questions relating to the patients' functional status dealt with the patients' ability to communicate and their orientation, behavior, tendency to wander, and activity at night. Fourteen (82 percent) of the patients were able to communicate their needs verbally. Three (18 percent) were unable to communicate their needs. Five (29 percent) were reported to be oriented most of the time while seven (41 percent) were described as being occasionally disoriented. Five (29 percent) were reported to be consistently disoriented. Appropriate behavior was listed for eleven (65 percent) of the patients. Inappropriate behavior, non-disruptive was reported for one patient (6

Table 3. Frequency Distribution of Subjects' Responses to Statements Regarding Patients' Urinary and Bowel Continence

| Type | Continence Statements | | | | | | | | Total | |
|-------|-----------------------|------|--------------------|------|------------------|------|-------------|-----|-------|-------|
| | Complete Control | | Occasional Mishaps | | Frequent Mishaps | | Incontinent | | # | % |
| | # | % | # | % | # | % | # | % | | |
| Urine | 5 | 29.4 | 5 | 29.4 | 6 | 35.3 | 1 | 5.9 | 17 | 100.0 |
| Bowel | 9 | 56.2 | 5 | 31.3 | 2 | 12.5 | 0 | 0.0 | 16* | 100.0 |

* One patient not included due to colostomy.

percent) while inappropriate, disruptive behavior was cited for five (29 percent) of the patients. Wandering, which was described as moving about aimlessly, was reported to be non-existent in thirteen (76 percent) of the patients. Two (12 percent) were noted to wander on occasion and two (12 percent) were described as wandering consistently. Nine (53 percent) were reported to remain quiet at night. Five (29 percent) occasionally got up and/or called out. Constant getting up and/or calling out was reported for three (18 percent) of the patients.

The amount of time that the caregiver spent in assisting the patient was also of interest to the investigator. The breakdown of time is presented in Table 4. Six subjects (35 percent) reported spending one to four hours per day caring for or assisting the patient. One subject (6 percent) listed a requirement of five to eight hours. Three subjects (18 percent) listed nine to twelve hours while two subjects (12 percent) reported an allocation of thirteen to sixteen hours per day. Four persons (24 percent) listed seventeen to twenty hours and one subject (6 percent) stated it was 24-hour duty.

Characteristics of the Caregivers

Demographic Characteristics

The mean age of the sample was 64.5 years and the median 67.7 years. The sample consisted of four males (24

Table 4. Frequency Distribution of Hours Per Day Allocated to Caring for the Patient as Reported by Caregivers

| Hours Per Day | Number of Caregivers | |
|----------------|----------------------|---------|
| | Number | Percent |
| 1 to 4 hours | 6 | 35.3 |
| 5 to 8 hours | 1 | 5.9 |
| 9 to 12 hours | 3 | 17.6 |
| 13 to 16 hours | 2 | 11.8 |
| 17 to 20 hours | 4 | 23.5 |
| 21 to 24 hours | 1 | 5.9 |
| Total | 17 | 100.0 |

percent) and thirteen females (76 percent). The distribution of the subjects by age and sex is displayed in Table 5. Five subjects (29 percent) were less than 60 years of age. Five subjects (29 percent) were between 60 to 69 years of age and seven subjects (41 percent) were greater than 70 years of age.

Three of the four males were spouses and the remaining male was a sibling. Three females were spouses, eight were daughters, and two were daughters-in-law.

Subjects' Health Status and Sleep Patterns

Table 6 presents the frequency distribution of subjects by health status at the time they began caring for the patient. Twelve persons (71 percent) reported their health as good while five persons (29 percent) reported their health as fair. Table 7 presents the frequency distribution of subjects' health status at the time their family member was admitted to the long term care facility compared to their health status prior to their caregiving responsibilities. None of the subjects reported better health while twelve subjects (71 percent) reported poorer health. Five subjects (29 percent) reported the same health status.

A single question describing their attention to their own health status during the time the subjects were caring for the patient revealed that fifteen subjects (88

Table 5. Frequency Distribution of Subjects by Age and Sex

| Age in Years | Sex | | | | | |
|--------------|------|------|--------|------|-------|-------|
| | Male | | Female | | Total | |
| | # | % | # | % | # | % |
| 20 - 29 | 0 | 0.0 | 1 | 5.9 | 1 | 5.9 |
| 30 - 39 | 0 | 0.0 | 0 | 0.0 | 0 | 0.0 |
| 40 - 49 | 0 | 0.0 | 1 | 5.9 | 1 | 5.9 |
| 50 - 59 | 0 | 0.0 | 3 | 17.6 | 3 | 17.6 |
| 60 - 69 | 0 | 0.0 | 5 | 29.4 | 5 | 29.4 |
| 70 - 79 | 4 | 23.6 | 3 | 17.6 | 7 | 41.2 |
| Total | 4 | 23.6 | 13 | 76.4 | 17 | 100.0 |

Table 6. Frequency Distribution of Subjects' Health Status
at the Time They Became Caregivers

| Health Status | Number | Percent |
|---------------|--------|---------|
| Good | 12 | 70.6 |
| Fair | 5 | 29.4 |
| Poor | 0 | 0.0 |
| Total | 17 | 100.0 |

Table 7. Frequency Distribution of Subjects' Health Status at Time the Patient Was Admitted to the Long Term Care Facility as Compared to Status Prior to Caregiving Activities

| Health Status | Number | Percent |
|---------------|--------|---------|
| Better | 0 | 0.0 |
| Same | 5 | 29.4 |
| Poorer | 12 | 70.6 |
| Total | 17 | 100.0 |

percent) continued to visit the doctor as often as necessary. One subject (6 percent) saw the doctor less often than necessary and one subject (6 percent) did not think it was necessary to see the doctor. None of the subjects reported being unable to visit the doctor when necessary.

Ten subjects (59 percent) reported receiving adequate sleep while seven subjects (41 percent) stated they did not have adequate sleep. The amount of sleep desired by caregivers ranged from six to nine hours. The number of sleep hours subjects reported are presented in Table 8. Two subjects (12 percent) reported getting three hours of sleep per day and four hours of sleep was reported by four subjects (24 percent).

Each subject was asked to describe the way they felt on most of the days when they were caring for the patient. Sixty-five percent of the subjects reported being somewhat tired (24 percent) or very tired (41 percent) on most of the days they were caring for the patient.

Alterations in Subjects' Lifestyle

Prior to caring for the patient, seven (41 percent) subjects reported spending one to four hours in the pursuit of personal interests and hobbies. Another seven reported spending five to eight hours in personal interest activities. Three persons (18 percent) reported having nine to twelve hours per day for similar activity. Following the

Table 8. Frequency Distribution of Subjects' Reported Hours of Sleep Per Day

| Hours of Sleep | Number | Percentage |
|----------------|--------|------------|
| Three | 2 | 11.8 |
| Four | 4 | 23.5 |
| Six | 2 | 11.8 |
| Seven | 5 | 29.4 |
| Eight | 3 | 17.6 |
| Nine | 1 | 5.9 |
| Total | 17 | 100.0 |

initiation of the caregiving responsibilities ten subjects (59 percent) reported one to four hours, two subjects (12 percent) reported five to eight hours, and five subjects (29 percent) reported the loss of all time for pursuit of personal interests and hobbies.

The subjects' ability to leave their homes was also affected by the caregiving role. Eleven (65 percent) of the subjects reported leaving the house every day prior to assuming the role of caregiver. Only three of the eleven subjects (18 percent) reported being able to go out every day afterwards. Five subjects (29 percent) reported a decrease of seldom to never.

The investigator was interested in who were the usual visitors in the household prior to caring for the patient and the effect that caring for an elderly disabled person had on the continuation of visitors. Table 9 presents the changes over time that occurred in relation to the usual visitors. Friends were the most frequently reported visitors. However, eight subjects reported a decrease in friends' visits over time while only one subject reported an increase and six subjects reported the number of visits as remaining the same. Family visits increased according to the reports of four subjects. The two subjects reporting a decrease in family visits noted this was per their request due to the behavior of the patient. One subject reported

Table 9. Number of Subjects' Responses to Statements
Regarding Changes in Visiting Patterns

| Visitors | Changes Over Time | | | | Total |
|----------------|-------------------|----------------------|-----------|------|-------|
| | Decreased | Remained the Same | Increased | N/A* | |
| Family | 2 | 6 | 4 | 5 | 17 |
| Friends | 8 | 6 | 1 | 2 | 17 |
| Neighbors | 1 | 3 | 2 | 11 | 17 |
| Church Members | 1 | 3 | 1 | 12 | 17 |

*N/A = No visits received

having no visitors before or after assuming the caregiving role.

Cancellation of vacation plans was reported by nine subjects (53 percent). Five subjects (29 percent) reported having to make adjustments in plans such as rescheduling or limiting the allotted time to coincide with a time when someone would be available to relieve them of the caregiving responsibilities. Four subjects (24 percent) reported the cancellation of retirement plans. Twelve subjects (71 percent) reported no change in retirement goals.

Subjects' Feelings

The subjects were asked to identify feelings which commonly occurred during the time they cared for the patient. The subjects were asked to specify if these feelings decreased, remained the same, or increased over time. The number of subjects' responses are displayed in Table 10.

The feelings of anger, anxiety, fatigue, frustration, pressure, sadness, and supportive were reported by between thirteen to fifteen of the subjects. Each of these feelings, with the exception of supportive, were also reported as increasing over time by the majority of subjects. The feelings reported as occurring to the least number of subjects were embarrassment, fulfillment, guilt, loneliness, and rewarded. All of the positive feelings (fulfillment, rewarded, satisfaction, supportive, valued,

Table 10. Number of Subjects' Responses to Statements Regarding the Occurrence of Feelings and Changes Over Time

| Feelings | Changes Over Time | | | | Total |
|---------------|-------------------|----------------------|-----------|------|-------|
| | Decreased | Remained the Same | Increased | N/A* | |
| Anger | 1 | 2 | 10 | 4 | 17 |
| Anxiety | 0 | 1 | 13 | 3 | 17 |
| Bewilderment | 0 | 7 | 3 | 7 | 17 |
| Confinement | 0 | 4 | 8 | 5 | 17 |
| Depression | 0 | 3 | 7 | 7 | 17 |
| Embarrassment | 1 | 3 | 1 | 12 | 17 |
| Fatigue | 1 | 2 | 10 | 4 | 17 |
| Frustration | 0 | 4 | 11 | 2 | 17 |
| Fulfillment | 1 | 1 | 4 | 11 | 17 |
| Guilt | 3 | 2 | 3 | 9 | 17 |
| Isolation | 0 | 4 | 5 | 8 | 17 |
| Loneliness | 0 | 5 | 2 | 10 | 17 |
| Pressure | 0 | 2 | 11 | 4 | 17 |
| Resentment | 2 | 3 | 7 | 5 | 17 |
| Rewarded | 1 | 1 | 4 | 11 | 17 |
| Sadness | 0 | 3 | 11 | 3 | 17 |
| Satisfaction | 2 | 5 | 5 | 5 | 17 |
| Supportive | 2 | 7 | 6 | 2 | 17 |
| Valued | 1 | 6 | 4 | 6 | 17 |
| Worthwhile | 1 | 6 | 5 | 5 | 17 |
| Other | 0 | 1 | 2 | 14 | 17 |

*N/A = No feelings identified

and worthwhile) were reported as decreasing over time by at least one or two subjects. The feelings reported under "other" were concern, conflict, and loss of own identity.

Living Arrangements

The living arrangements were of interest to the investigator. These are presented in Table 11. Seven subjects (42 percent) reported the patient moving into their homes. A bedroom was available in each of these cases. One caregiver reported that she and her husband had purchased a new home in order to have adequate space for her mother. Three subjects (18 percent) reported having moved into the patient's home. In two of these cases, the caregivers moved from other states in order to care for their mothers.

A move into a different home by both the patient and the caregiver was reported by two subjects (12 percent). Both cases involved older married couples. One husband had moved from the east coast in order to be close to his daughter so that she could assist him in the care of his wife. The other husband had moved to a mobile trailer home so he could manage both the upkeep of the house and the care of his wife.

Ten subjects (59 percent) reported being the only person in the household other than the patient. Seven subjects (41 percent) had a spouse who also resided in the household. Of these seven, one also reported the presence

Table 11. Frequency Distribution of Subjects' Responses to Statements Regarding Living Arrangements

| Living Arrangements | Number | Percent |
|---|--------|---------|
| Caregiver moved into patient's home | 3 | 17.6 |
| Patient moved into caregiver's home | 7 | 41.2 |
| Both patient and caregiver moved into a different home | 2 | 11.8 |
| No change occurred | 5 | 29.4 |
| Total | 17 | 100.0 |

of an adult son, one reported the presence of a father, and two of the subjects had one child each. One subject's child was in her teens and the other subject's child was a toddler. Fourteen (82 percent) of the subjects reported an increase in household tension during the time they were caring for the patient. Fourteen subjects (82 percent) also reported that other family members and friends were supportive of their contribution to the care of the patient. One subject (6 percent) reported family members as being critical of the care.

Financial Information

Eight subjects (47 percent) stated that their financial costs remained the same during the time they were caring for the patient. A significant increase in cost was noted by five subjects (29 percent). Two subjects (12 percent) reported a slight increase in costs. A significant decrease in financial output was noted by two subjects (12 percent). Both subjects had moved into the patient's home and were no longer responsible for the costs incurred in maintaining their own homes.

Only one subject (6 percent) reported having to resign employment in order to assume the role of caregiver. An out-of-state move resulting in a change in a spouse's employment was also noted by one subject (6 percent).

Employment was not affected for any other household or non-household family members.

Table 12 presents the subjects' annual household income. The annual income ranged from less than \$5,000 per year to greater than \$30,000 per year. One subject (6 percent) had an income less than \$5,000 per year; one (6 percent) had an income of \$5,000 to \$9,999; three (19 percent) had incomes of \$10,000 to \$14,999; two (13 percent) reported incomes between \$15,000 to \$19,999; one (6 percent) had an income of \$20,000 to \$24,999; one (6 percent) had an income of \$25,000 to \$29,999; and seven subjects (44 percent) had incomes of greater than \$30,000 per year.

Support Systems

Assistance Received in Caring for the Patient

Fourteen (82 percent) of the subjects reported receiving assistance in caring for the patient. The number who reported receiving the different types of assistance are presented in Table 13. More than one type of assistance was noted by the majority of subjects. Eight subjects reported receiving help with the physical care of the patient. Socialization, which was described as time spent talking with the patient, was reported by nine subjects. Surveillance was reported by twelve subjects; only two subjects reported any type of respite care.

Table 12. Frequency Distribution of Subjects' Annual Household Income

| Annual Income | Number | Percent |
|-----------------------|--------|---------|
| Less than \$5,000 | 1 | 6.3 |
| \$5,000 to \$9,999 | 1 | 6.3 |
| \$10,000 to \$14,999 | 3 | 18.7 |
| \$15,000 to \$19,999 | 2 | 12.4 |
| \$20,000 to \$24,999 | 1 | 6.3 |
| \$25,000 to \$29,999 | 1 | 6.3 |
| Greater than \$30,000 | 7 | 43.7 |
| Total | 16* | 100.0 |

* One subject did not answer.

Table 13. Frequency Distribution of Subjects' Responses to Statements Regarding Assistance Received in Caring for the Patient

| Types of Assistance Received | Number | Percent |
|---|--------|---------|
| Physical Care and Surveillance | 2 | 11.8 |
| Physical Care, Socialization and Surveillance | 4 | 23.5 |
| Physical Care, Respite, Socialization, and Surveillance | 2 | 11.8 |
| Socialization | 2 | 11.8 |
| Surveillance | 3 | 17.6 |
| Socialization and Surveillance | 1 | 5.9 |
| No Assistance | 3 | 17.6 |
| Total | 17 | 100.0 |

Seven subjects (41 percent) reported receiving assistance from health professionals. Family members who did not reside in the same household assisted six (35 percent) of the subjects. Friends and neighbors were also reported to assist in the care of the patient by five (29 percent) and four (24 percent) of the subjects, respectively.

Five (29 percent) of the subjects reported an increase in assistance over time. Eight subjects (47 percent) reported that the amount of assistance remained the same over time and one subject (6 percent) reported a decrease in assistance. Eight subjects (47 percent) reported having added time to relax and rest as a result of the assistance received. Three subjects (18 percent) reported no added time to relax and rest and three (18 percent) of the subjects reported less time to relax and rest due to the time spent in preparing for or assisting the person who was assisting with the patient care.

Assistance Received With Other Tasks

The usual tasks which the subjects were responsible for in addition to caring for the patient are presented in Table 14. All of the subjects were responsible for shopping. Sixteen of the subjects were also responsible for cooking, housekeeping, laundry, and transportation. The one subject not responsible for these tasks had a full-time

Table 14. Number of Subjects' Responses to Statement
Regarding Usual Tasks

| Usual Tasks | Number |
|---------------------|--------|
| Caring for Children | 3 |
| Cooking | 16 |
| Housekeeping | 16 |
| Laundry | 16 |
| Paid Employment | 4 |
| Shopping | 17 |
| Transportation | 16 |
| Other | 1 |

housekeeper. Four subjects were employed full time outside of the home. One subject was attending full-time school in addition to her caregiving and household responsibilities.

One subject (6 percent) reported receiving help with the tasks most of the time. Eleven (65 percent) of the subjects reported receiving help part of the time and five subjects (29 percent) reported receiving no help with tasks. Caring for children, housekeeping, transportation, and laundry were the areas where the largest percentage of help was received. Only one subject (6 percent) reported receiving help with cooking. Family members were the persons most frequently cited as assisting with the tasks. Eight subjects (47 percent) reported assistance from family members. Two subjects (12 percent) reported receiving assistance from neighbors. Only one subject (6 percent) reported either friends or social agencies as assisting with tasks. None of the subjects reported receiving assistance from church members.

Eight (47 percent) of the subjects reported the amount of assistance received as remaining the same over time; four subjects (24 percent) reported an increase in help over time. No decreases in assistance were reported. Three subjects (18 percent) reported an increase in their free time as a result of the assistance received with their tasks. Eight subjects (47 percent) reported that their free time remained the same and one subject (6 percent) reported

a decrease in free time due to the need to entertain those persons who were assisting with the tasks.

Services Utilized

The investigator was interested in knowing about the formal services that were used by the subjects. The subjects' thoughts about those services utilized or their reasons for not using the different services were also of interest to the investigator. The number of subjects responding to statements regarding the use or non-use of formal services is presented in Table 15.

Day care and meals on wheels were not utilized by any of the subjects. Twelve subjects did not think day care would have been beneficial; one subject was not aware that it was available; and three subjects did not think they could afford to pay for it. Fourteen of the subjects did not think meals on wheels would be beneficial and two subjects were not aware that such a service was available.

The home health aide and the visiting nurse were the services used by the greatest number of subjects. Six subjects used each of these services. Five of the subjects reported that the service provided much help. One subject reported that the home health aide service was more trouble than it was worth and one subject reported the same thoughts in regard to the visiting nurse service. Both subjects

Table 15. Number of Subjects' Responses to Statements Regarding Use of Services or Reasons For Not Utilizing Certain Services

| Thoughts About Services Used or Reasons For Not Using Services | Types of Services | | | | | | | |
|--|-------------------|----------------------|------------------|-----------|-----------------|--------------|---------------|----------------|
| | Day Care | Financial Assistance | Home Health Aide | Homemaker | Meals on Wheels | Respite Care | Support Group | Visiting Nurse |
| <u>Services Used</u> | | | | | | | | |
| Provided much help | - | 1 | 5 | 3 | - | 4 | 1 | 5 |
| Did not really help | - | - | - | - | - | - | 2 | - |
| More trouble than it was worth | - | - | 1 | - | - | - | - | 1 |
| <u>Services Not Used</u> | | | | | | | | |
| Did not think it would be beneficial | 12 | 14 | 8 | 11 | 14 | 7 | 9 | 9 |
| Was not aware that it was available | 1 | 1 | 2 | 1 | 2 | 4 | 4 | 1 |
| Did not think they could afford to pay for it | 3 | - | - | 1 | - | 1 | - | - |
| Total* | 16 | 16 | 16 | 16 | 16 | 16 | 16 | 16 |

*One subject did not answer.

reported that the person providing the service was unable to meet the needs of the patient.

Two subjects reported that the support group to which they belonged did not really help. In both cases the subjects attended peer support groups. Both subjects referred to the fact that while the group was gaining national recognition, which they supported, it did not assist them in learning how to meet the day-to-day needs of the patient.

The concern about the ability to pay for services was mentioned by one subject each in relation to homemaker service and respite care. Four subjects had utilized respite care and reported that it provided much help. Intermittent admissions into the long term care facilities were the types of respite care used by all of the subjects. The majority of the respondents stated that the reason they did not utilize the different services was that they did not think that the services would be beneficial. One subject did not answer the questions referring to the non-use of formal services. The subject stated that she considered it her duty to provide all of the care required by her mother even though she was sure the services would have been beneficial.

Each subject was asked to reflect on whether or not they thought that receiving help with the patient's care and the other tasks for which they were responsible would have

been beneficial. Twelve subjects (71 percent) reported that they thought receiving help with patient care would have been beneficial; the same number of subjects reported that they did not think receiving help with the other tasks would have been beneficial. Six subjects (35 percent) would have liked to have had daily assistance with the patient's care; five subjects (29 percent) thought that twice a week would have been sufficient. Eight (47 percent) of the subjects would have preferred health professionals to provide the assistance with patient care. One subject each (6 percent) would have preferred receiving the help from family, friends, or a combination of persons.

Availability of a Confidant

All of the subjects reported having someone with whom they could discuss their concerns. Friends were available to thirteen (76 percent) of the subjects. Four subjects each (24 percent) reported that they always felt better or usually felt better after discussing their concerns about caregiving with their friend or friends. Three subjects (18 percent) reported they never felt better and two subjects (12 percent) stated they usually felt worse.

Ten subjects (59 percent) confided in family members. Two (12 percent) of the subjects stated they always felt better; six (35 percent) reported they usually felt better; and two (12 percent) stated they never felt better.

The two subjects who reported never feeling better both suggested that family members did not understand what was involved in being a caregiver.

Five subjects (29 percent) reported discussing their concerns with health professionals. All of them stated they usually felt better afterwards. One subject (6 percent) had a neighbor to confide in and usually felt better after talking to the person. One subject (6 percent) reported discussing concerns with a social worker. The subject reported never feeling better after talking with the social worker and stated that this was due to the social worker's inability to alter the caregiver's situation.

Reasons for Admission

The subjects were asked to respond to an open-ended question regarding what specific thing(s) occurred or what the caregiver was thinking about that made him or her realize that the patient could no longer be cared for in the home setting. The responses were categorized and are presented in Table 16.

Deterioration of the caregiver's health and deterioration of the patient's functional status were the most frequently reported reasons for admitting the patient to a long term care facility. Ten subjects cited deterioration of their health and eight subjects reported a decline in the patient's functional status. Conflict in the household and

Table 16. Subjects' Responses to Statement Regarding Reasons for Admitting the Patient to a Long Term Care Facility

| Reasons for Admission | Number of Responses* |
|--|----------------------|
| Caregiver felt overburdened | 1 |
| Concern about harming the patient | 1 |
| Conflict in the household | 3 |
| Decreased caregiver morale | 1 |
| Deterioration of the caregiver's health | 10 |
| Deterioration of the patient's functional status | 8 |
| Failure to realize own goals | 2 |
| Inability to lift the patient | 3 |
| Increased patient wandering | 1 |
| Lack of assistance from family members | 3 |
| Patient made own decision to enter home | 2 |

*Total number of responses greater than seventeen due to more than one reason for some subjects.

lack of assistance from family members were also reported by three subjects. A decrease in physical stamina with the resultant inability to lift the patient was reported by three of the subjects.

Two subjects cited a failure to realize their own goals as reason for admitting the patient. The following statements are those which were expressed by the subjects:

"I was at the height of my career and had a new job opportunity."

"I wanted to live my own life."

Two subjects stated that the decision to enter the nursing home had been made by the patient. The remaining categories were derived from the following statements:

"I felt overburdened, I wasn't getting any assistance."

"She was increasingly abusive, I was afraid I might hurt her while protecting myself."

"My morale was being torn down."

"Her wandering was getting worse, one night she strayed and was gone for an hour before I found her."

Feelings Regarding Admission

The last question was designed to elicit the subjects' feelings about having admitted someone to a nursing home. A statement was made that a lot of people have real bad feelings after they admit someone to a nursing home. Each subject was then asked if they had any such feelings. Five subjects stated they did not have any bad

feelings. The following statements are those which were conveyed by these subjects:

"No, I feel better. He's where he can get proper care."

"No, it's an excellent place, there's good food and the care is excellent."

"She's well cared for, she's not lonesome and she's better off."

"I'm so thankful she's in there, if she'd have stayed she would have deteriorated. Now she's active and involved."

"No, I did the best thing for him, he's getting good care."

Twelve subjects responded affirmatively regarding bad feelings. Their statements were:

"Yes."

"I wonder if I've done the right thing."

"At first, but not now."

"At first, but now I realize she's better off."

"Yes, I really wanted to care for her. She was frightened to go. I had always planned to care for her."

"Yes, I had to put my mother in a nursing home and the care wasn't good. The care she's receiving is much better."

"I don't like nursing homes, I wouldn't do it unless it was absolutely necessary."

"I felt a little guilty, she may have thought we'd bring her back. I feel sad, but relieved."

"I felt very guilty. I cried myself to sleep every night. I still have guilt but she's happier now."

"Yes."

"Yes, I felt guilty, I even had my sister help me with the decision."

"Yes, she's giving me a bad time but it was all I could do."

Those subjects whose response did not include a reason for having such feelings were then asked, "Why do you think you have these feelings?" Among the responses were statements regarding feelings of guilt, concern that friends would be critical of the decision, and fear that the subject was not doing enough.

A final question, "Do you think they (your feelings) might be associated with guilt?" was asked of those subjects who had not yet mentioned guilt. Two subjects responded in the negative and two subjects stated that yes, they felt their feelings were associated with guilt. One subject did not respond verbally, but began to cry when asked the question.

Summary

The data was analyzed according to frequency distribution or number of subjects' responses to the various questions. Seventeen caregivers participated in the study. The caregivers cited a deterioration in their health status and a deterioration in the patients' functional status as the major reasons for seeking institutionalization.

CHAPTER 5

DISCUSSION OF FINDINGS AND CONCLUSIONS

This chapter includes the findings of the study as they relate to the review of the literature and the conceptual framework. Conclusions are drawn and recommendations for further study are made.

Findings in Relation to the Review of the Literature

A three part questionnaire was used in the study to identify factors involved in caregivers' decisions to place their elderly family members in long term care facilities. The areas studied included the functional status of the patient; alterations in the lifestyle of the caregiver; and utilization of support systems. Seventeen subjects participated in the study.

Functional Status

Functional status was operationally defined as a patient's physical and mental ability to carry out the activities of daily living. A deterioration in the patient's functional status was cited as a reason for admission by eight of the seventeen subjects. This supports the

findings of several authors (Bergmann, et al., 1978; Dunlop, 1980; and Swartz, 1982) who noted that a decline in functional status was often a precipitating factor in the caregiver's decision to seek institutionalization.

Specific areas of decline, including immobility, urinary incontinence, and disruptive behavior, have also been addressed by various authors. Sanford (1973) and Grad and Sainsbury (1963) wrote that the patient's level of immobility had a direct effect upon the caregiver's level of burden. Three of the subjects in the study reported their inability to lift the patient as a reason for admission. A need for maximum assistance in transferring was also reported by five subjects. Eight subjects reported that the patient required maximum assistance in ambulating or was unable to ambulate. This finding supports a similar finding by Smallegan (1981) that cited difficulty in ambulation as a major problem in persons being admitted to long term care facilities.

Urinary incontinence, which has also been suggested as a reason for placement (Freed, 1981; Maney, 1980; Demmerle and Bartol, 1980; and Vetter, Jones, and Victor, 1981) was reported as occurring consistently or frequently by seven of the subjects. However, none of the subjects specifically reported urinary incontinence as a reason for admission. This finding cannot be explained by the fact that the subjects may have grouped urinary incontinence

with other symptoms relating to the overall deterioration of the patient's functional status since only three of those subjects reporting urinary incontinence listed deterioration of the patient's functional status as a reason for institutionalization. The finding more likely supports Sanford's (1973) study of caregivers of the elderly which showed frequent reporting of urinary incontinence coupled with a high level of tolerance for the situation.

Physical and verbal abuse have been cited as serious problems by the caregivers of patients with dementia (Rabins, Mace, and Lucas, 1982; Morycz, 1980). This investigator did not limit the study to specific diagnostic categories nor was information relating to diagnoses obtained, however, five subjects reported that the patient's behavioral pattern was inappropriate and disruptive. Increased abusiveness was cited by one subject as a reason for seeking institutional care.

Caregiver's Lifestyle

Alterations in the caregiver's lifestyle were operationally defined as those changes affecting the physical, social, psychological, and environmental status of an individual which occurred during the time he or she functioned as a caregiver. The health status of the caregiver has been cited as a major factor influencing the decision regarding institutionalization (Davis, 1980; Goldstein, Regnery, and

Wellin, 1981). Ten subjects listed a deterioration in their health status as a major reason for admitting the patient to a long term care facility. This supports the findings of Golodetz, et al., (1969) who noted significant illness in 31 of 59 caregivers of persons with chronic illness and Sainsbury and Grad de Alarcon (1970) who noted that 58 percent of relatives of aged psychiatric patients reported physical health problems. Archbold (1980) also noted that 50 percent of the caregivers studied presented with at least one major health problem since assuming their role. The author further noted that caregivers tended to neglect their own medical care needs in order to care for the patient. The findings of this study differ from those of the author in that only one subject reported not being able to visit the doctor as often as necessary and no one reported being unable to visit the doctor when necessary. The difference in the findings may be explained by the fact that all of the caregivers studied by Archbold did not reside in the same household and therefore time was subjected to rigid scheduling in meeting the needs of the patient in addition to the needs of other family members.

Lack of sleep has been cited as contributing to the burden of the caregiver (Morcyz, 1980; Barnes, et al., 1981; Rabins, Mace, and Lucas, 1982; Sanford, 1973; Smallegan, 1981; Crossman, London and Barry, 1981; Zarit, Reever, and Bach-Peterson, 1980). Six subjects reported receiving less

than adequate sleep. This finding is lower than the 62 percent reported by Sanford (1973). A possible explanation for this may be the small size of the sample population.

Feelings of anger, sadness, depression, and fatigue were noted to be common among caregivers of patients with dementia (Rabins, Mace, and Lucas, 1982). Similar findings were noted in this study. Fourteen subjects reported feelings of sadness. Anger and frustration were listed by thirteen subjects. Ten of the subjects cited depression as a commonly occurring feeling.

Ten of the subjects (59 percent) reported being the only other person in the household. This finding is lower than the 42 of 59 households (71 percent) studied by Golodetz, et al. (1969). The difference may be due to the small sample size of this study.

The feeling of isolation was reported by a majority of the subjects. This supports the findings of Crossman, London, and Barry (1981) who listed isolation as a prevailing feeling among older women caring for disabled spouses. Loneliness was reported by seven of the seventeen subjects in this study. Interestingly, having someone else living in the household did not always eliminate the feelings of isolation or loneliness.

Fourteen subjects reported an increase in household tension during the time they were caring for the patient.

Household conflict was cited as a reason for seeking admission by three of the subjects. These findings support those of Brody (1966, 1981) wherein the author noted competing demands as leading to increased tension and conflict.

Five subjects reported a significant increase in financial costs. Three of the five had engaged health personnel in the care of the patient. Barnes, et al. (1981) and Morycz (1980) have identified increased costs as having an influence on the caregiver's burden. Three subjects listed the prohibitive cost of day care as the reason for not utilizing such a service. Cost was also considered in one subject's decision not to utilize homemaker services and one subject's decision not to pursue formal respite care. Overall, however, the income of the group was relatively high and a large number of the caregivers could afford to engage outside services. This finding limits the ability to generalize this study to a lower income population who cannot afford to purchase services.

Social Support

Social support was operationally defined as those persons and/or agencies which assisted the caregiver through the provision of goods and services or through listening, communicating, and sharing of information. All of the caregivers were family members. Fourteen of the subjects reported receiving help with the care of the patient. Eight

subjects listed family members as providing the help. This finding supports the findings of Brody, et al. (1978) and Minkler (1981) who cited family members as providing the greatest portion of care to the chronically ill. Twelve subjects also reported receiving help with tasks other than patient care. Here again, the family was most often cited as providing the assistance.

Norbeck (1981) has noted that there is a tendency for support to decrease over time when dealing with chronic conditions. Only one subject reported a decrease in the amount of help he was receiving. However, ten subjects cited decreases in the amount of visits from friends and family after they became caregivers. This change most probably reduced the overall number of persons available in the subject's pool of resources and would therefore support the author's view. Thoits (1982) also noted the occurrence of certain events as creating changes in existing support systems.

Findings in Relation to the Conceptual Framework

The conceptual framework for this study was based on the need for social support for the caregivers of the non-institutionalized elderly. The investigator believed that formal and informal supports would assist in alleviating the stresses associated with caregiving. Social support was

seen as an essential element in reducing the demands on the caregiver and meeting the needs of the caregiver. Unger and Powell (1980) and Snow and Gordon (1980) noted the need for social support in mediating the effects of stress.

Only one subject denied receiving any instrumental aid in meeting the increased demands of caregiving. This particular subject was only able to sustain the caregiving role for seven weeks. The mean length of time that the subjects in this study sustained their role was 3.6 years with a median of three years.

The need for relief from the demands of caregiving were cited by several authors (Lindsey and Hughes, 1981; Archbold, 1980; Goldstein, Regnery, and Wellin, 1981). Eight of the subjects interviewed reported receiving added time to relax and rest as a result of the assistance received. Three subjects reported an increase in free time.

Barnes, et al. (1981) noted the importance of having someone with whom the caregiver could share feelings and concerns. All of the subjects reported having at least one person with whom they could discuss their concerns. However, three of the subjects did not feel that the interaction assisted them in feeling better about the situation.

Conclusions and Implications

Several conclusions can be drawn from this study. The conclusions are relevant to the original purpose of the study. The purpose of the study was to identify factors involved in caregivers' decisions to relinquish their roles and thereby place the elderly in long term care facilities.

The majority of the caregivers in this study were in their late middle or older years. Twelve of the caregivers were 60 years of age or older. Older age is a period when most people have planned for a more relaxed, less worrisome existence. The caregiver, however, often finds him or herself enmeshed in a tightly scheduled, frustrating, anxiety producing situation. Nurses and other health care professionals must realize that as people age there is an accompanying decrease in their coping resources and support systems. Nurses working in the community and nurses involved in discharge planning of the elderly from hospitals and long term care facilities must go beyond concern for the patient's needs and assist the caregivers in learning how to cope with their new role.

A deterioration in the caregiver's health was a major reason for relinquishing the caregiving activities. Nurses and other health care professionals can assist in identifying the at-risk caregivers through an ongoing appraisal of the caregiver's physical and mental health

status. Resources which can reduce the demands and associated stresses placed on the caregiver can be identified. Recognizing problems, such as lack of adequate sleep, and assisting the caregivers in obtaining meaningful relief can aid in a reduction of health related problems for the caregiver.

The decline in the patient's functional status also prompted placement. Educating the caregivers as to the expected course of events associated with the patient's diagnosis will help to alleviate unwarranted fears. Teaching the caregiver how to perform unfamiliar tasks can diminish anxieties. Informing the caregiver about formal support services and letting them know that they don't have to do everything themselves can reduce guilt. All of these educational aims are in the realm of nursing.

An interesting finding of the study was the fact that most caregivers did not think the formal services would have been beneficial. This points out a need for health professionals to educate the public in regards to available services and how they can be used in the care of the elderly. The temporary or intermittent nature of such services as day care and/or respite care can provide relief for the caregiver. The use of such services can lead the caregiver to develop a level of confidence in support services which will meet the needs of the patient while also meeting the needs of the caregiver. The benefits of such use could

be measured through a reduction or delay in admission for those patients where a caregiver is present and he or she is receiving meaningful relief from the responsibilities of caregiving.

Recommendations

Based on the findings of the study, the following recommendations for further study are made:

1. Modify the criteria to include caregivers of patients admitted from the hospital. The exclusion of these caregivers limited the available subjects.
2. Reevaluate the questionnaire in terms of reducing the number of questions.
3. Replicate the study using a more diverse economic group and a larger population.
4. Investigate the relationship between the existence of social supports and the delay in admissions.
5. Explore specific changes which occurred to the patient over time. Identify specific physical and/or mental decrements which led the caregiver to seek placement.
5. Examine specific health changes experienced by the caregivers.

APPENDIX A
LETTER TO CAREGIVERS

DEAR

YOUR NAME WAS RECEIVED FROM THE _____

_____. I AM CONDUCTING A STUDY ENTITLED,
"FACTORS INVOLVED IN CAREGIVERS' DECISIONS TO PLACE THE
ELDERLY IN LONG TERM CARE FACILITIES." THE PURPOSE OF THE
STUDY IS TO IDENTIFY THE PHYSICAL AND MENTAL STATUS OF THE
PATIENT PRIOR TO ADMISSION, TO IDENTIFY WHAT CHANGES IN YOUR
LIFESTYLE OCCURRED AS A RESULT OF YOUR CAREGIVING RESPONSI-
BILITIES, AND WHAT TYPES OF SUPPORT WERE AVAILABLE TO YOU
DURING THE TIME YOU CARED FOR THE PATIENT. IT IS HOPED THAT
THE RESULTS OF THE STUDY WILL ASSIST NURSES AND OTHER HEALTH
CARE PROFESSIONALS TO UNDERSTAND SOME OF THE STRESSES AND
DIFFICULTIES ENCOUNTERED BY THE CAREGIVER IN PROVIDING CARE
TO AN ELDERLY PERSON IN THE HOME SETTING.

THE PURPOSE OF THIS LETTER IS TO REQUEST YOUR PARTICIPATION
IN THE STUDY. THE QUESTIONNAIRE WILL BE ADMINISTERED IN
YOUR HOME AT A MUTUALLY AGREED UPON TIME. THE STUDY IS
BEING LIMITED TO CAREGIVERS OF PATIENTS WHO HAVE BEEN
ADMITTED WITHIN THE PAST SIX MONTHS. I WILL BE CONTACTING
YOU WITHIN THE NEXT FEW WEEKS TO DISCUSS ANY QUESTIONS YOU
MAY HAVE AND TO INVITE YOU TO PARTICIPATE IN THE STUDY.
THANK YOU FOR YOUR CONSIDERATION.

SINCERELY,

APPENDIX B
DISCLAIMER STATEMENT

DISCLAIMER STATEMENT

YOU ARE BEING ASKED TO VOLUNTARILY GIVE YOUR OPINION ON THE STATEMENTS IN THIS QUESTIONNAIRE. BY RESPONDING TO THE QUESTIONNAIRE, YOU WILL BE GIVING YOUR CONSENT TO PARTICIPATE IN THE STUDY ENTITLED, "FACTORS INVOLVED IN THE CAREGIVERS' DECISIONS TO PLACE THE ELDERLY IN LONG TERM CARE FACILITIES." THE PURPOSE OF THE STUDY IS TO IDENTIFY FACTORS INVOLVED IN THE CAREGIVERS' DECISIONS TO RELINQUISH THEIR ROLES. IT IS HOPED THAT THE STUDY WILL ASSIST HEALTH CARE PROFESSIONALS TO BETTER UNDERSTAND THE ROLE OF THE CAREGIVER. YOUR NAME IS NOT ON THE QUESTIONNAIRE, AND ONLY THE INVESTIGATOR WILL HAVE ACCESS TO THE GATHERED DATA. YOU MAY CHOOSE NOT TO ANSWER SOME OR ALL OF THE QUESTIONS, IF YOU SO DESIRE. WHATEVER YOU DECIDE, THE CARE OF YOUR FAMILY MEMBER OR FRIEND WILL NOT BE AFFECTED IN ANY WAY. YOUR QUESTIONS WILL BE ANSWERED AND YOU MAY WITHDRAW FROM THE STUDY AT ANY TIME. THERE ARE NO KNOWN RISKS.

APPENDIX C
HUMAN SUBJECTS PROJECT APPROVAL FORM

THE UNIVERSITY OF ARIZONA COLLEGE OF NURSING

MEMORANDUM

TO: Mary T. Knight
8648 E. Palo Verde Dr.
Scottsdale, AZ 85253

FROM: Ada Sue Hinshaw, R.N., Ph.D. *ASH* Director of Research Jan R. Atwood, R.N., Ph.D.
Chairman, Research Committee

DATE: May 17, 1983

RE: Human Subjects Review: Factors Involved in Caregivers' Decisions to Place
the Elderly in Long Term Care Facilities

Your project has been reviewed and approved as exempt from University review by the College of Nursing Ethical Review Sub-committee of the Research Committee, and the Director of Research. A consent form with subject signature is not required for projects exempt from full University review. Please use only a disclaimer format for subjects to read before giving their oral consent to the research. The Human Subjects Project Approval Form is filed in the office of the Director of Research, if you need access to it.

We wish you a valuable and stimulating experience with your research.

ASH:des
4/83

APPENDIX D
QUESTIONNAIRE -- PART I

QUESTIONNAIRE -- PART I

THE FOLLOWING QUESTIONS ARE TO OBTAIN SOME INFORMATION ABOUT THE PATIENT FOR WHOM YOU WERE CARING PRIOR TO HIS/HER ADMISSION INTO THE NURSING HOME. I WILL READ YOU THE QUESTION AND THEN I WILL RECORD YOUR ANSWER.

1. What is the patient's age? _____
2. What is the patient's sex? _____ Male _____ Female
3. What is your relationship to the patient? _____
4. How long have you taken care of the patient? _____
5. How long ago was the patient admitted to the nursing home?
_____ Days _____ Weeks _____ Months

THE NEXT SET OF QUESTIONS REFERS TO THE FUNCTIONAL ABILITIES OF THE PATIENT AT THE TIME OF ADMISSION TO THE NURSING HOME. THE QUESTIONS WILL HAVE SPECIFIC RESPONSES. I WILL GIVE YOU A CARD WHICH LISTS THE RESPONSES AND I WOULD LIKE YOU TO CHOOSE THE RESPONSE THAT IS CLOSEST TO THE RIGHT ANSWER.

6. Did the patient require any assistance in bathing?
_____ Required no assistance
_____ Required minimal assistance (such as, washing back)
_____ Required maximum assistance (such as, back, legs, arms)
_____ Required total assistance (unable to assist)

7. Did the patient require any assistance in dressing?

- Required no assistance
- Required minimal assistance (such as, tying shoes)
- Required maximum assistance (such as, putting on clothes)
- Required total assistance (unable to dress or not dressed)

8. Did the patient require any assistance in walking?

- Ambulated unassisted
- Ambulated with minimal assistance (such as, a cane)
- Ambulated with maximum assistance (such as, constant physical aid)
- Unable to ambulate (bed or chair bound)

9. Did the patient require any assistance in transferring?

- Transferred unassisted
- Transferred with minimal assistance (such as, lying to sitting)
- Transferred with maximum assistance (such as, total lift)
- Unable to transfer (bed bound)

10. Did the patient require any assistance in eating?

- Required no assistance
- Required minimal assistance (such as, cutting meat)
- Required maximum assistance (such as, putting food on utensil)
- Required total assistance (had to be fed)

11. Which of the following best describes the patient's control of (his/her) urination at the time (he/she) was admitted to the nursing home?
- Complete control of urination
 - Occasional mishaps
 - Frequent mishaps
 - Incontinent of urine
12. Which of the following best describes the patient's control of (his/her) bowel elimination?
- Complete control of bowels
 - Occasional mishaps
 - Frequent mishaps
 - Incontinent of bowel elimination
13. Which of the following best describes the patient's ability to communicate?
- Communicates verbally
 - Communicates non-verbally only
 - Does not communicate needs
14. Which of the following best describes the patient's awareness of time, place, and person?
- Oriented to time, and/or place, and/or person most of the time
 - Occasionally disoriented to time, and/or place, and/or person
 - Consistently disoriented to time, and/or place, and/or person

15. Which of the following best describes the patient's behavioral pattern?

- Appropriate behavior
- Inappropriate behavior, non-disruptive (such as, laughing)
- Inappropriate behavior, disruptive (such as, abusive, aggressive)

16. Did the patient wander? (Move about aimlessly)

- Did not wander
- Wandered on occasion
- Wandered consistently

17. Which of the following best describes the patient's activity at night?

- Remains in bed quietly
- Occasionally gets up and/or calls out
- Constantly getting up and/or calling out

18. How many hours per day did you usually spend assisting the patient?

- One to four hours
- Five to eight hours
- Nine to twelve hours
- Thirteen to sixteen hours
- Seventeen to twenty hours
- Twenty-one to twenty-four hours

APPENDIX E
QUESTIONNAIRE -- PART II

QUESTIONNAIRE -- PART II

THE QUESTIONS IN THIS NEXT SECTION ARE TO OBTAIN SOME INFORMATION ABOUT YOU, THE CAREGIVER.

19. What is your present age? _____
20. How do you think your health was at the time you began caring for the patient?
- _____ Good
- _____ Fair
- _____ Poor
21. How would you rate your health at the time the patient was admitted to the nursing home as compared to when you began caring for the patient?
- _____ Better than when you began caring for the patient
- _____ The same as when you began caring for the patient
- _____ Poorer than when you began caring for the patient
22. Which of the following best describes your attention to your own health status during the time you were caring for the patient?
- _____ Continued to visit the doctor as often as necessary
- _____ Continued to visit the doctor less often than necessary
- _____ Was unable to continue to visit the doctor when necessary
- _____ Did not think it was necessary to visit the doctor

23. Did you think that you had adequate sleep at the time you were caring for the patient?
- _____ Yes
- _____ No
24. How many hours of sleep would you have liked to have had? _____
25. How many hours of sleep did you get? _____
26. Which of the following best describes the way you felt on most days when you were caring for the patient?
- _____ Very rested
- _____ Somewhat rested
- _____ Somewhat tired
- _____ Very tired
27. Prior to caring for the patient, how many hours per day did you spend in pursuing personal interests and hobbies?
- _____ One to four
- _____ Five to eight
- _____ Nine to twelve
- _____ Other (please specify)
28. After you started caring for the patient, how many hours per day were spent in pursuing personal interests and hobbies?
- _____ One to four
- _____ Five to eight
- _____ Nine to twelve
- _____ Other (please specify)

29. Prior to caring for the patient, how often did you leave the home?

- _____ Every day
- _____ Once or twice a week
- _____ Once or twice a month
- _____ Other (please specify)

30. After you started caring for the patient, how often did you leave the home?

- _____ Every day
- _____ Once or twice a week
- _____ Once or twice a month
- _____ Other (please specify)

31. List all the persons who usually visited you prior to caring for the patient.

_____, _____, _____
 _____, _____, _____
 _____, _____, _____

32. For each of those listed, which of the following best describes their visits during the time you were caring for the patient?

- _____ decreased over time (1)
- _____ remained the same (2)
- _____ increased over time (3)

| | | | | | | | |
|-------|---|---|---|-------|---|---|---|
| _____ | 1 | 2 | 3 | _____ | 1 | 2 | 3 |
| _____ | 1 | 2 | 3 | _____ | 1 | 2 | 3 |
| _____ | 1 | 2 | 3 | _____ | 1 | 2 | 3 |
| _____ | 1 | 2 | 3 | _____ | 1 | 2 | 3 |

33. Did any of the following feelings commonly occur while you were caring for the patient?

- | | | |
|--------------------------------------|---------------------------------------|--|
| <input type="checkbox"/> Anger | <input type="checkbox"/> Anxiety | <input type="checkbox"/> Bewilderment |
| <input type="checkbox"/> Confinement | <input type="checkbox"/> Depression | <input type="checkbox"/> Embarrassment |
| <input type="checkbox"/> Fatigue | <input type="checkbox"/> Frustration | <input type="checkbox"/> Fulfillment |
| <input type="checkbox"/> Guilt | <input type="checkbox"/> Isolation | <input type="checkbox"/> Loneliness |
| <input type="checkbox"/> Pressure | <input type="checkbox"/> Resentment | <input type="checkbox"/> Rewarded |
| <input type="checkbox"/> Sadness | <input type="checkbox"/> Satisfaction | <input type="checkbox"/> Supportive |
| <input type="checkbox"/> Valued | <input type="checkbox"/> Worthwhile | <input type="checkbox"/> Other (Specify) |

34. For each of those feelings you listed, which of the following best described them over time?

decreased over time (1)

remained the same (2)

increased over time (3)

| | | | | | | | |
|-------|---|---|---|-------|---|---|---|
| _____ | 1 | 2 | 3 | _____ | 1 | 2 | 3 |
| _____ | 1 | 2 | 3 | _____ | 1 | 2 | 3 |
| _____ | 1 | 2 | 3 | _____ | 1 | 2 | 3 |
| _____ | 1 | 2 | 3 | _____ | 1 | 2 | 3 |
| _____ | 1 | 2 | 3 | _____ | 1 | 2 | 3 |
| _____ | 1 | 2 | 3 | _____ | 1 | 2 | 3 |
| _____ | 1 | 2 | 3 | _____ | 1 | 2 | 3 |

THE FOLLOWING QUESTIONS ARE TO OBTAIN INFORMATION ABOUT THE SETTING IN WHICH THE CARE TOOK PLACE AND SOME OF THE COSTS INVOLVED IN THE CARE.

35. Which of the following living arrangements were necessary so you could take care of the patient?

_____ You moved into the patient's home

_____ The patient moved into your home

_____ Both moved into a different home

_____ No change occurred

_____ Other (please specify)

36. If the patient moved into your house, which of the following occurred?

_____ There was an available bedroom

_____ A family member had to give up their room

_____ A family area was transformed into a bedroom

_____ Other (please specify)

37. How many other adults lived in the house at the time you were caring for the patient? _____

38. What was their relationship to you? _____,

_____, _____, and _____

39. How many children lived in the house at the time you were caring for the patient? _____

40. What was their relationship to you? _____,

_____, _____, and _____

41. Which of the following best describes your usual living situation while you were caring for the patient?

- Tension in the household increased
- No significant change in household tension
- Tension in the household decreased

42. Which of the following best describes the reactions of other family members/friends toward you when you were caring for the patient?

- Supportive of your contribution to the care of the patient
- Noncommittal toward your contribution to the care of the patient
- Critical of your contribution to the care of the patient

43. Which of the following occurred in respect to your financial costs during the time you were caring for the patient?

- Significantly increased
- Slightly increased
- Remained the same
- Slightly decreased
- Significantly decreased

44. Which of the following best describes employment changes necessitated by caring for the patient?

A. You, the caregiver

- had to resign employment (1)
- no change in employment (2)
- had to take on employment (3)

B. Other household members

- _____ 1 2 3
- _____ 1 2 3

C. Non-household family members

_____ 1 2 3

_____ 1 2 3

D. Others

_____ 1 2 3

_____ 1 2 3

45. What was the annual household income during the time you were caring for the patient?

- _____ Less than \$5,000
- _____ \$5,000 to \$9,999
- _____ \$10,000 to \$14,999
- _____ \$15,000 to \$19,999
- _____ \$20,000 to \$24,999
- _____ \$25,000 to \$29,999
- _____ Greater than \$30,000

46. Which of the following best describes the effect that caring for the patient had on vacation/retirement goals?

Vacation:

- _____ Cancellation of all plans was necessary (1)
- _____ Adjustment in plans was necessary (2)
- _____ No change in plans was necessary (3)

Retirement: 1 2 3

APPENDIX F
QUESTIONNAIRE -- PART III

QUESTIONNAIRE -- PART III

THE FOLLOWING QUESTIONS ARE TO OBTAIN INFORMATION ABOUT SOCIAL SUPPORTS WHICH ASSISTED YOU DURING THE TIME YOU WERE CARING FOR THE PATIENT. THESE QUESTIONS REFER TO WHAT GENERALLY OCCURRED.

47. Did anyone assist you in caring for the patient?

_____ Yes

_____ No

48. If yes, which of the following best describes the type of assistance received?

_____ Physical care (bathing, feeding, ambulating)

_____ Respite care (took patient for part of day or overnight)

_____ Socialization (spent time talking with the patient)

_____ Surveillance (sitter)

49. Which of the following persons assisted by caring for the patient?

_____ Church members

_____ Family, household members

_____ Family, non-household members

_____ Friends

_____ Health professionals

_____ Neighbors

_____ Other (please specify)

50. Which of the following best describes the usual amount of assistance received in caring for the patient?

Increased with time

Remained the same

Decreased with time

51. Which of the following best describes having someone help take care of the patient?

Gave me added time to relax and rest

Did not give me added time to relax and rest

Gave me less time to relax and rest

52. Which of the following tasks were you usually responsible for in addition to caring for the patient?

Caring for children

Cooking

Housekeeping

Laundry

Paid employment

Shopping

Transportation

Other (please specify)

53. Did anyone usually assist you by sharing these tasks?

All of the time

Most of the time

Part of the time

None of the time

54. If yes, which of the following tasks were usually shared?

- Caring for children
- Cooking
- Housekeeping
- Laundry
- Paid employment
- Shopping
- Transportation
- Other (please specify)

55. Which of the following persons assisted in sharing your tasks?

- Church members
- Family
- Friends
- Neighbors
- Social agencies
- Other (please specify)

56. Which of the following best describes the amount of assistance received in sharing your tasks?

- Increased with time
- Remained the same
- Decreased with time

57. Which of the following best describes having someone share your tasks?

- Increased my free time
- Free time remained the same
- Decreased my free time

58. Did you utilize the following service while you were caring for the patient?

Day Care?

_____ Yes

_____ No

59. If yes, how much help did it provide you?

_____ Provided much help (1)

_____ Didn't really help (2)

_____ More trouble than it was worth (3)

60. If no, which of the following best describes your thoughts about them?

_____ Thought they would not be helpful (1)

_____ Was not aware that they were available. (2)

_____ Thought I could not afford to pay for them. (3)

61. Financial assistance? _____

If yes, 1 2 3

If no, 1 2 3

62. Home Health Aide? _____

If yes, 1 2 3

If no, 1 2 3

63. Homemaker Services? _____

If yes, 1 2 3

If no, 1 2 3

64. Meals On Wheels? _____

If yes, 1 2 3

If no, 1 2 3

65. Respite Care? _____

If yes, 1 2 3

If no, 1 2 3

66. Support Group? _____

If yes, 1 2 3

If no, 1 2 3

67. Visiting Nurse? _____

If yes, 1 2 3

If no, 1 2 3

68. Other (please specify) _____

If yes, 1 2 3

If no, 1 2 3

69. Which of the following best describes your thoughts about receiving help with the care of the patient?

_____ I think it would have been beneficial

_____ I do not think it would have been beneficial

70. If you think it would have been beneficial, how often would you have liked to have received the help?

_____ Every day

_____ Twice a week

_____ Once a week

_____ Other (please specify)

71. From whom would you have liked to have received the help?

_____ Family (any specific members)

_____, _____, _____

_____ Friends (anyone in particular)

_____, _____, _____

_____ Health professionals (who in particular)

_____, _____, _____

_____ Other (please specify)

_____, _____, _____

72. Which of the following best describes having someone help you with tasks other than caring for the patient?

I think it would have been beneficial

I do not think it would have been beneficial

73. If you think it would have been beneficial, how often would you have liked to have received the help?

Every day

Twice a week

Once a week

Other (please specify)

74. From whom would you have liked to have received the help?

Family (any specific members)

_____, _____, _____

Friends (anyone in particular)

_____, _____, _____

Neighbors (anyone in particular)

_____, _____, _____

Social agency (which ones in particular)

_____, _____, _____

Other (please specify)

_____, _____, _____

75. During the time you were caring for the patient, did you have anyone with whom you could discuss your concerns?

Yes

No

76. If your answer is yes, who was this person or persons?

- Family member
- Friend
- Health professional
- Neighbor
- Social worker

77. For each of those listed, which of the following best describes having someone to discuss your concerns with?

- I always felt better after talking to the person (1)
 - I usually felt better after talking to the person (2)
 - I never felt any better after talking to the person (3)
 - I usually felt worse after talking to the person (4)
 - I always felt worse after talking to the person (5)
- | | |
|------------------------------------|------------------------------------|
| <input type="checkbox"/> 1 2 3 4 5 | <input type="checkbox"/> 1 2 3 4 5 |
| <input type="checkbox"/> 1 2 3 4 5 | <input type="checkbox"/> 1 2 3 4 5 |
| <input type="checkbox"/> 1 2 3 4 5 | <input type="checkbox"/> 1 2 3 4 5 |

THESE FINAL TWO QUESTIONS DO NOT REQUIRE SPECIFIC RESPONSES. I WILL READ YOU THE QUESTIONS AND I WOULD LIKE YOU TO ANSWER THEM IN YOUR OWN WORDS AND I WILL RECORD YOUR ANSWERS.

78. Were there any specific things that occurred or that you were thinking about that made you realize that you could no longer care for your _____ in your home?

79. A lot of people have real bad feelings after they admit someone to a nursing home. Do you have any such feelings?

Why do you think you have these feelings?

Do you think they might be associated with guilt?

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