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AS RELATED TO SELECTED CAREGIVER CHARACTERISTICS

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Linda S. Campbell

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of the requirements for

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# CAREGIVER PERCEPTION OF BURDEN AS RELATED TO SELECTED CAREGIVER CHARACTERISTICS

By

Linda S. Campbell

A THESIS

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

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College of Nursing

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# ABSTRACT

## CAREGIVER PERCEPTION OF BURDEN AS RELATED TO SELECTED CAREGIVER CHARACTERISTICS

By

Linda S. Campbell

A descriptive cross sectional study of 307 caregivers of impaired elderly individuals was conducted to determine the perceived impact on caregivers' lives in the dimensions of schedule, health, finance, and family abandonment. The caregivers' perceptions of impact on their lives were analyzed in relation to such variables as caregiver sex, caregiver income and education, and family relationship of the caregiver to the elderly care recipient. Data were utilized from an earlier research study (Given and Given, 1985). A self-administered Caregiver Inventory for perceptions of feelings was completed by the respondents. The analysis of variance and multiple regression were employed in the statistical analysis. The inferences were that: 1) female spouse caregivers perceive more impact on schedule and health than male spouse caregivers; 2) spouse caregivers perceive more impact on schedule than non-spouse caregivers; 3) non-spouse caregivers perceive more family abandonment than spouse caregivers; and 4) spouse income is related to financial impact and abandonment.

To my husband, Bob,

and to our children,

Bruce and Judy

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## Introduction

Caring for a chronically ill, elderly person is usually a progressive, all-consuming activity which cannot be incorporated into a caregiver's life without significant impact on his/her sense of self, time, freedom, career, and relationships with others. In general, families assume a caregiving role without an understanding of what is involved, or of the consequences of the role (Archbold, 1982). Some facts, statistics, and trends will be presented in the next few pages, in order to describe the importance to health professionals and legislators of evaluating the facets of caregiving.

According to the projections in the "Information Please Almanac" (Johnson, 1987), there will be 35.4 million people between the ages of 60-79 and 10.1 million people 80 years or over by the year 2000. Day (1985) highlights the trends of the societal changes that are reshaping our family roles and are affecting the nature of aging in the United States. "More Americans are living past their 85th birthdays, making the 85+ age groups the fastest growing segment of the United States population" (Day, 1985, p. 1). By the eighth and ninth decade of life, the chances of being functionally impaired in some way, and in need of health and social services increases significantly. "The number of disabled elderly Americans is expected to more than double between 1985 and 2020" (Day, 1985, p.1).

The old are living longer because of improved technology. Thus, instead of the problems of the elderly being acute and short-term, they are multiple, chronic, and long-term. "In 1985, approximately 6.6 million Americans aged 65 and older are in need of long-term care. Of this group, 1.4 million are living in nursing homes, and another 5.2 million are living in the community with disabilities" (Day, 1985, p. 6). That may leave them in need of long-term care from families or friends.

The major share of support and/or care is provided to the elderly by the family. Increase in life expectancy, delayed marriages, and fewer children per family are increasing the ratio of parents to children who are available to look after them (Day, 1985). "Families (not government or agency programs) provide between 80 and 90 percent of medically-related care, home nursing, personal care, household maintenance, transportation, and shopping" (Day, 1985, p. 4). According to Day (1985), families are not abandoning their kin. Brody (1985) projects, "Over five million people are involved in parent-caring at any given time" (p. 21). It is projected that there will be 225 elderly (85+) per 1000 offspring by 2000 (Day, 1985).

The elderly receive personal care first from the spouse (if living), then from a daughter, if the elderly person is a widow or widower, and then from a sibling, when other family members are not available. Women comprise 70 to 80 percent of the caregivers (George, 1984). The fact that women are the main caregivers is supported in the literature (Archbold, 1982; Brody, 1981; Snyder & Keefe, 1985; George & Gwyther, 1986; Hawranik, 1985; and Brody, 1985). "Most of the sons and male relatives are turned to for advice on business matters, help with transportation and home maintenance" (Day, 1985, p. 5).

It is possible that there may be more than one adult child helping an impaired elderly member, but there is usually one family member who is considered the primary caregiver. Also, the adult child may be providing care or support to more than one parent, for example, a parent and parent-in-law (Callahan, 1980). The larger proportion of elderly who are institutionalized are there either because they have no close relatives available or they suffer from disabilities that are too difficult to handle at home.

Many caregivers are aging themselves. The average age of spouses providing care for a husband or wife was 65 in the early 1980's, with 30 percent of the caregivers ages 74 and older (Montgomery, 1984). "Most adult children providing care to the very old are over 50", according to Day (1985, p. 8). Decrease in strength and endurance, and the beginning of health problems can arise in the over 50 age group. Brody (1985) also discusses the fact that the largest proportion of daughters caring for their parents are in their 40's and 50's. According to research done by Brody (1985), "40 percent of people in their late 50's had a surviving parent, as did 20 percent of those in their late 60's" (p. 20).

As mentioned, families are providing most of the support for the functionally impaired elderly. The cash values of services performed by families far exceeds the combined costs of government and professional services to elderly, both living in the community or living in institutions.

"A 1984 report to the Federal Council On Aging estimated that the support provided to a disabled elderly family member accounted for the equivalent of full-time work in between 30 and 40 percent of households providing care" (Day, 1985, p. 8). An estimate of retirement income in comparison to costs of a spouse providing care to a partner was not given. Brody (1985) also mentions funding as an issue for many families. In some families, the caregiver has to quit his/her job in order to provide care for the elderly person, or he/she may have to assume the added responsibility of a job in order to keep the family financially solvent.

Financial costs are not the only problems of caregiving. There are emotional stressors, conflicts in family relationships because of demand on time and lack of privacy, disruption of living patterns, disruption of family routines, and physical strains (George & Gwyther, 1986; Fitting, Robins, Lucas & Eastham, 1986; Cantor, 1983; Johnson, 1983; and Snyder & Keefe, 1985).

Archbold (1980) cites social isolation as a universal problem for the caregivers. The requirements for care, especially of those elderly with very limited physical or mental capacities, change the life style and activities of the caregiver. There is a general decrease in freedom of mobility and time because of the tasks, such as bathing, dressing, exercising, feeding, meal preparation, symptom control, and providing transportation. Social activities are often decreased and 'spur of the moment' activities are impossible.

Archbold (1982) states that "the caregiver for an older family member faces sustained or increasing dependency with no predictable end" (p. 13). Women can suffer from unrelieved heavy physical labor of caregiving. Cantor (1983) cites that spouses may be the highest risk group among caregivers because they are older themselves, therefore, they are predisposed to health problems, and they have no children at home to assist them. There is a potential for isolation and psychological stress. Day (1985) verifies that many wives are often lonely, isolated, and exhausted. Snyder and Keefe (1985) state that caregivers in their study "described life style changes in terms of the inability to get regular exercise, the inability to plan for the future, the loss of time for one's self, 'cabin fever', the loss of interest in all activities, the loss of a sex life, and the loss of friends" (p. 6). Other health problems were also mentioned, such as pulled muscles, headaches, allergies, and hernias.

These problems, of financial strain, emotional and physical strain, and multiple demands on the caregiver need to be addressed. The role of the family caregiver providing support for the elderly will increase as the numbers of very old and potentially dependent elderly grow.

Therefore, in thinking of the impact caregiving has on a person's life, the research question to be addressed in this thesis is, "Upon controlling for variation in the elderly person's functional health status, how are selected caregivers' characteristics related to perception of burden?". Several dimensions of burden will be explored, and they are: impact on schedule, impact on finances, impact on health status, and impact from family abandonment. The selected characteristics of the caregiver (sex, socioeconomic status, and relationship to the elderly person) will be analyzed for each dimension. In the following section, the definitions of these concepts and characteristics will be given.

## Definitions of Concepts

The concepts that will be identified are perceived burdens, the caregiver, the elderly person, and the characteristics of the caregiver. The independent variables (the characteristics) are sex,income level and educational level of the caregiver, and the relationship of the caregiver to the elderly impaired person. The dependent variables are the perceived burdens. The elderly person's functional status will be added as another independent variable. The reason for the addition of another variable is to examine if the relationship of caregiver characteristics to perceived burdens is affected by a variation in the elderly person's functional ability.

The definitions of the concepts are as follows:

1. Perceived burdens will be identified as the impact of caregiving in the following areas: 1) impact on one's schedule; 2) impact on one's health status; 3) impact on one's finances; and 4) impact from family abandonment.

a. Impact on daily schedule will be identified as when the caregiver feels that he/she must eliminate things from his/her schedule, feels that he/she is unable to enjoy or participate in social or community activities, and feels that there are interruptions in his/her work or activities in order to provide care.

b. Impact on health status will be identified as when the caregiver feels that the activities of caregiving, and managing the elderly person's medical care results in a change of health status for the caregiver. For example, the caregiver feels tired all of the time from problems of caring for someone or the caregiver's health has become worse since caring for the elderly person.

c. The impact on financial status will be identified as when the caregiver feels that the additional expenses incurred, such as purchasing of medical care, medical supplies, and services, has placed a financial strain on the family.

d. An impact from family abandonment will be identified as when the caregiver feels that caring for an elderly family member places a strain on family relationships. Factors that can be identified as impact on family relationships are when the caregiver believes that other family members have left he/she alone to care for an elderly family member, or family members depend too much on him/her to care for the elderly relative.

2. The caregiver in this study will be identified as a spouse, adult child, or other family member who self-acknowledges that he or she is primarily responsible for caring for a debilitated elderly person.

3. The elderly individuals who are in need of care are considered to be persons 64 years of age or over who have at least one chronic disease, and must need assistance with two activities of daily living (such as toileting or dressing),and/or activities such as shopping and housework.

The characteristics of the caregiver will be operationalized in the following way:

1. The sex of the caregiver respondent will be determined by the individual identifying his/her sex in the screening instrument.

2. The relationships of the caregiver to the elderly person will be defined as the adult child, spouse, child-in-law, siblings and other relatives. In considering in-laws, the primary responsibility for caring for the elderly impaired person may be the daughter or son, but in the case of the son, it is often his wife (the daughter-in-law) who has the responsibility for the care of his mother or father. The other relative will include grand daughter, a

sibling, niece, nephew, brother-in-law or sister-in law, or cousin.

3. The <u>income level</u> will be identified as the total income of a household. If the spouse is a caregiver, the total income of the husband and wife will be used. For the non-spouse caregivers, the total household income of the caregiver, and the total income of the elderly recipient of care will be identified separately. Income can be identified within $1,000 increments up to $10,000, then every $4,999 (e.g. within $10,000 - $14,999) increments up to $30,000. All those above $30,000 will be in the same level. (NOTE: The median income of families in 1983 was $24,580 [Keane, 1987]).

4. The educational levels will be divided into grade school or less, some high school, completion of high school, some college or technical training, completion of college, and graduate or professional schooling.

## Functional Status Variable

The <u>functional health status</u> of the elderly recipient of care is the independent variable that will be added to show variation in the patient's functional ability. This variable will be identified through questions regarding the patient's functional level as measured by the activities of daily living, instrumental activities of daily living, and mobility. The functional status of the elderly person is used in this study because various levels of impairment can affect the degree of involvement of care provided. In other words, those elderly more disabled probably require more assistance than those less impaired.

Snyder and Keefe (1985) suggested that the "higher the level of disability, the more likely the caregiver reported suffering health problems" (p. 5). Even though the statement by Snyder and Keefe only addresses the health status of the caregiver, it demonstrates that functional status of the elderly person can have an impact on the life of a caregiver. As mentioned earlier, the elderly person must have one chronic disease and be deficient in two ADL's (toileting, feeding, etc.), and/or instrumental activities of daily living such as shopping. (These are addressed in a questionnaire.)

## Hypotheses

The hypotheses are as follows:

1. For patients with similar functional status, there is a relationship between the caregiver's perception of impact on one's schedule and the characteristics of sex, income level, and educational status of the caregiver and the relationship of the caregiver to the elderly person.

(Sex) a. The female caregiver perceives more negative impact on her schedule than the male caregiver. Horowitz (1985) found that son caregivers less often felt that their time for leisure activities had been affected by caring for a parent (22% compared to 56% of daughters). The female caregiver may be involved with family or occupational obligations so there are more competing demands on her time. If she is an older caregiver, she is free from child-rearing

responsibilities, so she feels an impact on her schedule when she is obligated to care for the spouse. There is less impact on male caregivers even though they perceive a difference in life style. They receive more assistance from relatives or children than the female caregiver, because caregiving is not an expected role of the male (Johnson, 1983). Both Johnson (1983) and Snyder and Keefe (1985) found that male caregivers utilized help from formal providers more so than female caregivers. Brody (1985) in a survey of three generations of women found that both working and non-working women provided roughly equal amounts of care to their impaired mothers. Twenty-eight percent of the women quit their jobs and also felt that caregiving interfered with time with their husbands. There is an expectation in our society that women assume the role of caregiver even if she has other obligations.

(Income and Education) b. Caregivers in the lower socioeconomic groups perceive more <u>impact</u> on schedule than caregivers in the higher socioeconomic groups. Callahan, Diamond, Giele and Morris (1980) state that "lower income groups provide physical care, household help,child-minding, and recreation, while middle-income groups tend to help financially" (p.39) in these types of activities. Archbold (1982) found that caregivers in lower income ($7,000-$9,999) had to adhere to a rigid schedule. Those in higher income level ($15,000 - $19,999) used more community resources and services. Archbold (1982) documented that the caregivers with a higher educational level (such as lawyers, physicians, and nurses) have more access officially and unofficially with a range of social supports. McAuley (1984) concluded from a study on in-home-care for elderly individuals that "people with greater education and social resources receive more services" (p. 62), probably because they are more knowledgeable regarding access to health care resources. In considering the fact that those with higher education receive more services, caregivers of these individuals might perceive less impact on daily schedule.

(Relationship) c. Adult child and other relative caregivers perceive greater impact on schedule than the spouse caregivers. The adult child perceives more impact on his/her schedule because of more competing commitments such as family and/or occupational obligations. Johnson (1983) demonstrated that adult child caregivers (married and unmarried) have a higher percentage of social obligations than the spouse or other relative caregivers (adult child, 53%; spouse, 23%; and other relative, 28%; $\underline{p} < .001$). The adult children expressed that their parent's illness had an affect upon their social lives. George and Gwyther (1986) document that "adult-child caregivers report the lowest level of visits with family and friends and time spent relaxing" (p.256). The spouse caregiver will perceive less impact than the adult child because they are generally older and have less familial or occupational obligations.

2. For patients with similar functional status, there is a relationship between the caregiver's perception of <u>impact or one's finances</u> and the characteristics of sex, income level and educational level of the caregiver, and the relationship of the caregiver to the elderly person.

(Sex) a. The female caregiver perceives more impact on finances than the male caregiver. Some female caregivers might have to resign from a job in order to care for an elderly person. Brody (1985) states, "that twenty-eight percent of our sample of non-working women had quit their jobs because of their elderly mothers' needs for care" (p. 25). Studies were not found that documented specifically an impact on financial status by sex.

(Income and Education) b. The caregivers in the lower socioeconomic groups perceive more impact on finances than those in the higher socioeconomic groups. Lower income groups have less income for resources and services. Those in the lower group may be able to receive assistance through federal or state programs, such as Medicaid. Those in the middle income group are often not eligible for any kind of assistance. Archbold (1982) discussed that care providers, who are usually in the lower socioeconomic group (compared to care managers), feel they had diminished benefits and increasing costs as a result of caregiving. Chenoweth and Spencer (1986) found that "lack of finances meant that care at home was only the alternative, and in-home help was not affordable" (p. 270). Therefore, there would be more impact on the caregiver's financial status in the middle and lower income groups.

McAuley (1984) states that education is probably indicative of a higher socioeconomic status, so those with a higher education perceive less impact in finances than those with less years of education. Those with higher levels of education probably have more financial resources available to them. According to Exter (1987) good education often results in a good income.

(Relationship) c. The spouse caregiver perceives greater impact on financial status when compared to the adult child or other relative. George and Gwyther (1986) report that spouse caregivers have significantly lower household incomes than the adult child and other types of caregivers. The adult child or other relative such as niece or nephew (if younger) may have opportunity to increase their income. If the caregiver is a same age peer, such as sibling, impact would be same as spouse caregiver. The spouse caregiver is living on a fixed income. Cantor (1983) found that spouses reported a greater degree of financial strain than the adult child or other relative because the spouse caregiver's household income was the lowest. In 1984 most of the aged family groups continued to have poverty rates that were high compared with those of other adults (Radner, 1987). "Within the group aged 65 or older, the older family units (a unit of two or more persons) improved their position slightly relative to the younger age units, but in 1984 their incomes remained far below those of the younger age units" (Radner, 1987, p. 55). In 1984 the poverty rate for aged persons continued to exceed the poverty rate for each age group in the 25-64 age range (Radner, 1987). According to Exter (1987) even though median household incomes had greatest gain between 1980 and 1985 and occurred among those 65 and over, incomes drop with increasing age after age 54. For example, the median income of households headed by 55 to 64 year olds is $25,600; among householders aged 65-74, the median income is $15,400; among those aged 75 and over, the median income is $10,500 (number of household members not provided).

3. For patients with similar functional status, there is a relationship between the caregiver's perception of impact on his/her health status and the characteristics of sex, income level, educational level of the caregiver, and the relationship of the caregiver to the elderly person.

(Sex) a. The female caregiver perceives more impact on health status than the male caregiver. Johnson (1983) reported that husbands probably experience less strain because others help more with the provision of care. Men are not expected to participate as much in domestic functions, therefore, they receive more assistance. Also, men request more help from formal providers, so feel less strain. Horowitz (1985) reported that 31% of son caregivers thought less often that their emotional health had changed for the worse ($\underline{n} = 32$, $x_2 = 7.5$, $\underline{p} < .05$) in comparison to daughter caregivers. The younger female caregiver has several roles to fill such as mother, wife, and possibly an occupational role. Too many competing demands can cause stress and change in health status. Snyder and Keefe (1985) found that elderly women, who are mostly the caregivers, lived on low fixed incomes and many social services are not covered under Medicare or insurance plans. Also, women tend to view such things as housework as their duty, so do not hire anyone even when caregiving becomes too burdensome. Thus, the women, especially the elderly female caregivers, are at higher risk for suffering health problems. (Since females are considered to be the predominant caregivers, there is not a lot of literature on affects of caregiving on males.)

(Income and education) b. Caregivers in the higher socioeconomic group perceive less impact on health status than those in lower socioeconomic group. Those in the higher socioeconomic group have more means and resources in order to utilize health services; also, those in the higher socioeconomic group may be able to afford assistance, so feel less fatigue, stress, or strain from caregiving. McAuley and Arling (1984) found that people with greater education and more social resources utilized more services. Education is probably indicative of knowledge about services (McAuley and Arling, 1984, p. 62). There were not any studies found on how caregivers in various income levels perceived the impact on their health status.

(Relationship) c. The spouse caregiver perceives more impact on health status than adult child or other relative caregivers. Cantor (1983) suggests that spouses may be the highest risk group (from physical strain from caregiving) because they are older themselves and predisposed to health problems. Johnson and Catalano (1983) documented that 17% (of 115) of spouse caregivers had reported a decline in health after eight months of caring for a disabled spouse. (Adult-child caregivers reported no significant change.) Adult children, even though they may have many demands (employment, family) are probably younger, and may have more assistance available if living with spouses or children. The spouse is generally alone with the impaired person and doesn't have any relief readily available. Also, the spouse caregivers are usually older and suffer from more chronic disease or are predisposed to illness. If the other relative caregiver is a sibling and the same age peer as the care-recipient, the perception of impact on health status might be the same as the spouse caregiver. Cantor (1983) documents that spouse caregivers perceived their health to be fair or poor (84%), adult children perceived their health to be good or fair (95%), and other relatives perceived their health to be good or fair (82%).

4. For patients with similar functional status, there is a relationship between the caregiver's perception of the impact from family abandonment and the characteristics of sex, income levels and educational levels of the caregiver and the relationship of the caregiver to the elderly person. (Little documentation was found on the impact on family relationships as affected by sex, income level, educational level, and relationship of the caregiver, except general statements that there are strains on family relationships while providing care to an elderly person.)

(Sex) a. The female caregiver perceives more impact of family abandonment than the male caregiver. The male often receives more assistance from other family members because the caregiving role is not an expectation for the male (Johnson, 1983; Horowitz, 1985). The female is expected to care for an impaired elderly person and so may resent the fact that other family members are not helping; thus, causing a disruption in family relationships. The female is also expected to continue her obligations as a mother and wife if she is a younger adult-child caregiver, thus, feeling others are leaving her alone to care for the elderly person. Brody (1985) reported that working daughters were more likely expected to adjust their work schedules for parent care than working sons were expected to adjust their work schedules. The expectation of a woman being a caregiver can lead the woman to perceive she is being "dumped on" by the other family members. The single female (adult child or other relative) could particularly perceive abandonment if she is also employed and has no one readily available to assist her.

(Income and Education) b. Caregivers in the higher socioeconomic groups perceive less family abandonment than those in the lower socioeconomic groups. Scott et al. (1986) found that the majority of caregivers of Alzheimer's patients reported a predominately positive feeling of social-emotional support from family. The average yearly income of this group of caregivers was $24,000 to $29,000. Worcester and Quayhagen (1983) documented that lower income caregivers view the care and responsibility of parents as less burdensome than middle classes. The satisfaction could indicate family support, but there is very little documentation on perception of family abandonment among lower, middle, or upper income groups.

(Relationship) c. The spouse caregiver perceives greater impact from family abandonment than the adult child, or other relative. The adult child possibly has more family members around her, so perceives less abandonment. Chenoweth and Spencer (1986) stated that "sometimes the primary caregiver was resented by others in the family who denied the problems" (p.270) of the recipient of care. Johnson and Catalano's (1983) and Poulshock and Deimling's (1984) studies indicate that more dependent care-recipients and more disruptive care-recipients had a negative effect on caregiver's relationship with family members. Types of relationships of caregivers to elderly individuals were not included in this study. The authors did not differentiate types of caregivers. The spouse caregiver (or same age peer caregiver) may feel abandoned by family members if little assistance is given because he/she is living alone with the impaired person.

## Purpose of Study

The purpose of this study is to look at how certain characteristics of the caregiver affect the caregiver's perception of impact on his or her life while caring for an elderly adult. In this study, feelings will be explored as to whether the caregiver believes that caregiving to an impaired elderly adult has an impact on his/her schedule, physical and mental status, finances, and family abandonment. The recognition of what the caregivers feel are burdens of caring for an individual in the home, will contribute to the process and need of collecting consistent data so that health professionals can develop support systems and identify strategies to help caregivers cope. In this way, adequate documentation can help establish the need for legislative and policy changes regarding caregiving and the need for supportive services in the community for caregivers. Consistent data are needed to adequately document that there are burdens to caregiving for an elderly adult with a chronic disease. Also, a profile of the characteristics of those with certain dimensions of impact may be identified. The research can also enable the clinical nurse specialist to begin to become sensitive to the burdens, and thus, help develop strategies in working with caregivers.

## Assumptions

There are some assumptions in this study. First, it is assumed that the questions presented to the caregivers participating in the study will be relevant and meaningful to the participant. Second, it is assumed that the individual caregivers will answer the questions honestly and openly. Third, it is assumed that the caregivers are able to recognize and identify perceived burdens of caregiving such as impact on schedule, or impact on finances and abandonment.

## Limitations

In dealing with the limitations of the study, there are several factor to discuss. One limitation involves the blending of different variables and/or groups together, thus obscuring the differences among each group. The study will involve caregivers from both rural and urban areas. There will not be an attempt to separate the perceived burdens of the rural caregivers from the urban caregivers. There is no definitive information in the instrument to identify the rural caregivers from the urban caregivers. The limitation is that perceptions of burdens might be different for each group, but the differences will not be shown in this study.

Certain variables will not be addressed in this study such as personality traits of caregiver, length of time of caregivers marital status (except when caregiver is obviously a spouse), and any support from agencies or groups. These variables may also have an affect on perception of impact as a result of caregiving along with the variables addressed. The functional status of the elderly person will be addressed, but not the type or severity of the elderly person's illness.

In the instruments used in the study, the questions are close-ended. The items may not reflect all of the feelings or experiences of the example of caregivers.
In this study, the perceived impact on the lives of caregivers caring for someone under the age of 64 is not addressed. Those who cannot read or write are generally excluded from the study unless the individual has someone available to assist him/her in completing the written questionnaires.

There are two other factors that will cause limitations in this study. The first one is that the relationship of the caregiver and the chronically-ill elderly individual before his/her illness and before his/her dependency on the caregiver will not be explored. Thus, there is a limitation on knowing whether the relationship prior to caregiving activity has an affect on the perception of the caregiver during caregiving involvement. The second factor is that the participating caregivers in the study are asked to volunteer for the study. Volunteers may perceive caregiving differently than those who refuse to participate. Therefore, the burdens perceived in the study may not be truly representative of all caregivers.

## Overview

In Chapter I, the growth of the elderly population, who are potentially individuals with either functional or mental impairment, and the problem of caregiving for an elderly person in the United States were introduced. There are five remaining chapters in the thesis. In Chapter II, concept development will be presented. The review of literature involving each concept of caregiver, caregiver characteristics, burdens, and the elderly person will be presented in Chapter III. The latest research studies and the results of the studies will be discussed in order to lend support for the study. The research design used, the population and the instrument used, and the data collection procedures used will be presented in Chapter IV. In Chapter V, the presentation of data, the analysis of the data, and the results of the study will be discussed. The interpretation of the results and the implications of the findings for advanced nursing practice, research, education, and primary care will be presented in Chapter VI.

# Chapter II

# CONCEPTUAL FRAMEWORK

## Overview

The purpose in Chapter 2 is to develop each concept of the problem statement. The specific problem is: "How are selected caregiver characteristics related to perception of burden?" Therefore, the concepts of caregiver, of elderly person, and of perceived burdens will be presented. Each concept will first be defined and then secondly developed through evidence reviewed in literature. Within the concept of caregiver, the characteristics of age, sex, and socioeconomic status and the relationship of the caregiver to the elderly person will be addressed. In the section on the elderly person, some information on functional status will be included. Through a literature review, the relationship will be shown among the concepts.

## Caregiver

The caregiver is identified as a spouse, adult child, or other family member, who is self-acknowledged as being primarily responsible for providing care to an elderly person. According to most studies, the typical "caregiver" for the elderly is a woman, in her 40's or 50's, with a husband and children to look after, or she may be a grandmother experiencing the inevitable changes of aging (Brody, 1985). She may have to attend to a chronically ill elderly person in her home day and night. Day (1983) states that "the majority of offspring caring for a disabled elderly parent are over age 50. The average age of spouses caring for a disabled partner is 66, with more than 30 percent being over age 74" (p. 1). The spouse, being older, may also suffer from a chronic illness or disability.

According to Archbold (1982), even though caregiving is a family endeavor, one family member is usually identified as the caregiver. In general, this responsibility falls to the spouse, where one exists, or to a daughter or daughter-in-law. Caregiving, according to Archbold (1982), is considered women's work. Johnson (1983) found "that the principal of substitution rather than shared functioning among family members is more common, which means that serial availability of relatives exists in descending order from intimate to distant relationships" (p. 382). In other words, if the spouse is available, he or she provides the care; among widows, the child is the one who provides care; and among the childless or unmarried, other relatives provide the care. Johnson (1983) also discussed that if the spouse was the caregiver rather than the adult child, the patient was less likely to be institutionalized, and less conflict and stress was reported. According to Johnson and Catalano (1983), the spouse provides the most comprehensive care. An adult child often has competing commitments. When the older person has to depend on more distant relatives, there is less involvement in care by the other relatives.

There are two roles of caregiving according to Archbold (1982): care providers who perform the work themselves and care managers who obtain and manage the services of others. Care providers, will be identified as caregivers throughout the study.

Brody (1981) states, "that additional research has confirmed the identity of the principal caregivers. Belatedly, 'alternatives' to institutional care are now being advocated, the natural or informal support system has been discovered and the 'family' is being cheered on in its caregiving role" (p. 472). These phrases are probably euphemisms for adult daughters (and daughter-in-laws), who are the true alternatives. Brody (1981) adds that if the impaired older person has a spouse, the vast majority of services are provided by the spouse, together with the adult daughter or daughter-in-law. When the older person is widowed, and almost nine million older persons are widowed, the women in the next generation are the principal caregivers. Also, older people in need of help look to daughters rather than sons for assistance and services, such as to shop and run errands, to give personal care, to plan meals, to administer medications, to transport to physicians' offices, and to mobilize, coordinate and monitor any services from other sources. Men may give assistance with household maintenance type tasks. Day (1985) supports this by stating that "women make up about between 70 and 80 percent of the caregivers. Sons and male relatives are turned to for advice on business matters, help with transportation, and home maintenance (p. 5).

In considering spouse caregivers, who generally provide the most comprehensive care, there may be a male caregiver. Female-spouse caregivers and male-spouse caregivers have usually been studied together. There have only been a few studies that have analyzed differences in impact on the lives between male and female caregivers (Fitting, Robins, Lucas, & Eastham, 1986; Zarit, Todd, & Zarit, 1986; Snyder & Keefe, 1985; and Johnson, 1983). It is generally assumed that females are usually the caregivers, as mentioned earlier, but Cantor (1983) found that slightly over half of the spouse caregivers in her study were male. Men may perceive a different impact from the caregiving role, since they are not accustomed to handling household responsibilities. Women may resent the role of caregivers in later years, because they look at their later years as a time for more personal growth. In other words, they no longer have child-rearing responsibilities.

Caregivers may endure severe economic, personal, and social stress in caring for their elderly relatives. According to Johnson (1983), there is a dyad in the caregiving unit, the donor (caregiver) and the recipient of the support, unless there happens to be a larger unit of family that cooperates and interchanges the caregiving role. Caregivers are subject to stress and strain and at risk for becoming over burdened. Government programs and policies do little to support caregivers in the home.

Little information in the literature review is given as to whether there are those in certain socioeconomic levels, who tend to provide care for an elderly impaired person. Archbold (1982) found that care managers (those who obtain and manage the services of others) have a higher socioeconomic status (income, education, and occupation). The care provider may be torn between his/her obligations to work and obligations to the elderly person. Those in the higher socioeconomic level may have a broad range of social supports, such as lawyers, physicians, nurses, and social workers, more so than those in the lower socioeconomic level. Most of the studies such as Zarit, Todd, and Zarit (1986), Cantor (1983), and Chenoweth and Spencer (1986), provide information on how many caregivers are in certain socioeconomic levels, but do not provide information on impact on caregivers' lives in relation to socioeconomic status.

Therefore, in summary, the caregiver is typically a woman in her 40's or 50's, with husband and children, or she may be a grandmother experiencing the inevitable changes of aging (Brody, 1985). The average age of a spouse caring for a disabled partner is 66. One family member is usually identified as the caregiver, and in general the responsibility falls to the spouse, if one exists, or to a daughter or daughter-in-law. According to Archbold (1982), caregiving is women's work. The family is being cheered on in the caregiving role, but the daughter or daughter-in-law is usually the responsible caregiver. There are male caregivers, generally a spouse, but few studies have been done on difference (if any) of perceived impact between male and female caregivers. Also, there is little information on differences of perceived impact of caregiving according to socioeconomic status. In this study, the perception of impact by the caregiver in relation to age, sex, socioeconomic status, and relationship of caregiver to the elderly person will be addressed.

## Elderly Person

In thinking of the elderly person, Beck and Phillips (1983) define elderly individuals as "frail when because of mental or physical limitations, they no longer can independently meet all of their daily needs" (p. 97). The elderly are often afflicted with multiple functional and chronic problems. Garner and Mercer (1982) cite that in nursing homes 55 percent may have cognitive deficits and residents generally have four chronic or crippling disabilities, such as cardiovascular disease, ranking first with organic brain syndrome, fractures, and arthritis. Orthopedic problems can cause the elderly person to be confined to bed or chair. The conditions can be of a degenerative and disabling nature. Johnson and Catalano (1983) found that with continuing poor health, and dependence upon others, the elderly person's mood and satisfaction with social supports decline. Therefore, more conflict with the caregiver develops.

Feller (1983) states that "the need for the help of another person increases sharply with age, especially among the elderly. Fewer than one in ten who are 65-74 years of age need help, compared with four in ten who are 85 years of age or over" (p. 1). For example, the rate of needing help in at least one basic physical activity (walking, going outside, bathing, dressing, using toilet, getting in and out of bed and chair) was higher among persons in the older age group (65-74 yrs.-52.6 per 1000 persons; 75-84 yrs. - 114.0 per 1000 persons; and 85+ yrs. - 348.4 per 1000 persons, [Feller, 1983]). The rate per thousand people who had a device to control bowel movements or urination or other trouble controlling bowel movements or urination increased with age. A sharp increase in older people usually staying in bed was shown between 65-74 years of age (11.3/1000) and 75 years and over (30.4/1000). The information just presented, means that a caregiver may have to handle or manage daily activities, incontinency, lifting, and turning, along with managing health problems. "At present, family members provide 80 percent of all personal care and medically related services" (Archbold, 1982, p. 12).

Impaired elderly require social services, nursing care, nutrition, and personal aid. These services are often not reimbursable (Medicare has strict criteria for reimbursing skilled nursing and aid services); their family members provide the care. If family assistance is not available, the elderly person is placed in a nursing home (Peck, 1983). The degree of impairment of the elderly person may affect the perception of caregiver burden. George and Gwyther (1986), Sushil (1985), and Snyder and Keefe (1985) indicate that those caring for a more seriously impaired elderly person (more serious symptoms, more dependencies in ADL's) experience a greater sense of social and physical burden and a high level of stress.

According to Day (1985), there has been a significant increase in the ratio of the elderly 85 and older to their adult children. The increase is as a result of longer life expectancy, delayed marriages, and the fall in the number of children per family. The increased ratio will likely continue to occur over the next two decades. Therefore, the ratio of <u>disabled</u> elderly (over 85) to their offspring will continue to rise. Many of the elderly, who need help, are very old and most are widowed. The adult children, primarily daughters, are the caregivers to the elderly dependent adults.

Disability and the need for assistance rises with advancing age. With the advances in medical technology, acute medical symptoms are brought under control, but people live longer with a chronic disease. Therefore, the impaired elderly person needs assistance at home since they have some lost mental or physical abilities. Day (1985) states that "the major health needs of the elderly have changed from those associated with acute short-term illness requiring skilled nursing care in hospitals to needs associated with multiple chronic conditions requiring the use of drugs and help with ordinary daily activities" (p. 6).

In summary, the elderly recipient of care is frail, who because of mental and physical incapacities can no longer live independently. Approximately 80 percent of those over 65, have some type of chronic illness, and those over 85 years of age may be widowed. These impaired elderly persons require nursing care, personal care, and social services, which are often provided by a family member (most likely an adult daughter). In this study, the elderly person must be 65 years of age or older, have at least one chronic disease, and must need assistance with an activity of daily living or with an activity such as shopping or housework. The functional health status of the elderly person will be explored in this study, because the patient's health status may have an affect on the caregiver's perception of impact on his/her life.

## Burdens

The concept of burden has been identified as an impact on one's schedule, an impact on one's health status, an impact on financial status, and an impact from family abandonment. If a middle aged (40-50 years) daughter is caring for an elderly disabled parent, there is often an impact on the family finances, family relationships, on daily freedom such as shopping or social activities, and on the caregiver's energy level. A middle aged woman is beginning to realize a decline in her energy level. A spouse caregiver is usually older so he/she also has less stamina, and may have developed some physical problems of his/her own. Spouses are also usually more isolated, in that they are alone with their partners.

Worcester and Quayhagen (1983) reviewed studies that showed "multiple situational stresses in caring for elderly family members have resulted in decreased satisfaction with the caregiver role" (p. 62). the caregiver may have to handle both psychological and physical problems. He/she may have to be the decision-maker for the elderly person. The other burdens can be financial costs, exhaustions, conflicting demands on time, disruption of family routines and relationships, and disruption of living patterns, such as work, recreation and participation in social and community activities. There can be social isolation, particularly for a spouse (Day, 1985).

On the other hand, according to Archbold (1980), some caregivers do not perceive caregiving as disruptive to their life style. They view it as being a positive and self-satisfying experience. The more positive attitude may be attributed to those caregivers who have been providing care for a short period of time or are caring for an elderly person who is not severely incapacitated. In the following pages, the various dimensions of perceived burdens of caregiving will be addressed.

### Impact on Schedule

The impact on schedule has been identified as when the caregiver feels that he/she must eliminate things from his/her schedule, feels that he/she visits family and friends less frequently, and feels that there are interruptions in work or activities in order to provide care.

Archbold (1982) discusses that decreased freedom in mobility and time, such as inability to participate in social activities and an adherence to a rigid schedule, is one of the costs of caregiving. There is a decrease in freedom on a daily basis and a loss of freedom in a larger sense, such as being unable to make any long-range life plans. The loss of daily freedom is accentuated when the parent or elderly person cannot be left alone. Minimal involvement from other family members would help alleviate the strain, but often caregivers of an elderly parent are single women or women without family support, and therefore, have no respite from caregiving (Archbold, 1982).

The caregiver may not feel free to invite friends into the home, either because of embarrassment over the behavior of the elderly person, or because of the amount of tasks that have to be completed (e.g. bathing, feeding, dressing, and treatments). All activities may be centered around providing care for the elderly recipient. He/she may only have a limited time for shopping because of the need to complete such tasks as feeding, exercising the elderly person, or bathing on a regimented schedule or in a timely manner. It may be unsafe to leave the elderly person alone because of his/her mental or physical incapacity. Therefore, there has to be someone in the home at all times. The caregiver can feel trapped. He/she has to plan all activities; no activities, such as shopping, can be done spontaneously. They may be unable to enjoy time for themselves due to the number of tasks that need to be accomplished not only for the family but for the elderly person. Even when substantial assistance from an agency is available to the caregiver, the fact that relief time is not in their control prevents them from enjoying or utilizing the freedom (Archbold, 1982). Those in the lower socioeconomic group may not have the financial resources to obtain any respite. Also, those in the higher socioeconomic group may have activities which they have to limit because of providing care to an elderly relative.

As mentioned, there can also be a loss of freedom in the larger sense, such as being unable to make any long-range life plans (Archbold, 1982). Relocation, retirement plans, and vacations can be affected. Because of the financial cost of caregiving, the caregiver might not be able to take a vacation; or because of no respite care, either from the extended family or community, the caregiver cannot leave home for a vacation. The elderly person may have always lived in one location where he/she has a family physician aware of his/her condition. Therefore, relocation is difficult because of the inconvenience of finding a new doctor to handle the elderly individual's problems. A move, for the caregiver or caregiver's family, may also be impossible because the impaired elderly person, living in the caregiver's home, cannot tolerate a move physically or emotionally.

Parental anxiety over something happening to the caregiver can increase the caregiver's frustration and loss of freedom. The care recipient might want to know all details of the caregiver's activities, therefore, adding to the caregiver's sensation of feeling trapped.

Therefore, in summary, an impact on one's schedule can be an adherence to a rigid time schedule, being unable to enjoy or to participate in social or community activities, a lack of spontaneity in doing activities, a feeling of entrapment in the home, and in a larger sense, inability to make future plans for a vacation, retirement, or a move to another geographic area. In this study, the caregiver's perception of impact on schedule, such as interruption of activities, visiting with friends and family less, and eliminating activities from his/her schedule, will be explored. The impact of caregiving may be perceived differently by caregivers with different characteristics, such as sex, socioeconomic level, and relationship to the patient.

### Impact on Health Status

The impact on health status has been identified as when the caregiver feels that the activities of caregiving, and managing the elderly person's medical care results in a change of health status for the caregiver. For example, the caregiver feels that he or she is constantly tired as the result of the problems of caring for someone or the caregiver's health has become worse since caring for the elderly person. The activities of caregiving can lead to mental and physical exhaustion. The caregiving activities of bathing, dressing, providing transportation, and housekeeping may involve 24 hours per day. Heavy physical labor may be needed for bathing, lifting, transferring from a bed to chair, cleaning from incontinence, or managing aggressive or paranoid behavior. Women in the caregiving role can suffer from unrelieved heavy physical labor of caring for an incapacitated person. Other activities may be the management of constipation or diarrhea, feeding the person, and planning a well-balanced diet. Many caregivers have no training in these skills and develop strategies by trial and error (Archbold, 1982).

Other functions of the caregiver are that he/she must be an advocate for medical care and be involved in financial decisions for the recipient. Caregivers may deprive themselves of medical care and rest periods because of the added responsibilities and/or cost of caring for an elderly person (Archbold, 1980).

According to Day (1985), "most wives providing care bear the burden with little outside help. Many of them are lonely, isolated, and exhausted, and in need of help and support as much as the spouses they are looking after" (p. 8). Many caregivers are themselves aging. The average age of spouses providing care for an impaired husband or wife was 65 in the early 1980's (Day, 1985). Increased age predisposes caregivers to poor health or change in health status. Also, as one ages, one's energy level is less. Cantor (1983) pointed out that spouses are the highest risk group among caregivers, because they are likely to be old themselves. The dyad of husband and wife are usually living alone so all the personal care of the incapacitated spouse, the housework and shopping are done by one person. Johnson (1983) reported that husbands experience less strain than the wife-caregivers, but there is little documentation on whether male caregivers feel more or less change in health status than female caregivers. Adult child caregivers may perceive less impact on health status because they are generally younger, and have less health problems than the spouse-caregivers.

Exhaustion and physical problems can develop. Snyder and Keefe (1985) report in a study that physical and mental exhaustion were one of the top health problems of the caregiver. "The longer persons have been caregiving, the greater the chances that they are also suffering health problems" (Snyder & Keefe, 1985, p. 10). Also, the caregiver may already have a chronic illness, such as arthritis or diabetes, which is compounded by the role of caregiving. In summary, the impact on health status will be identified as to whether the caregiver feels that the activities of caregiving, such as bathing, feeding, housework, and managing the elderly person's medical care, leads to feelings of fatigue and whether caregiving results in a change in health status for the caregiver. The caregiver may deny themselves health care and periodic rest because of the overwhelming responsibility of caregiving. In this study, the caregiver's perception of a feeling of fatigue and of feeling that his/her health status has declined will be explored. The perception of impact of caregiving in relation to the sex, socioeconomic status and relationship of the caregiver to the elderly person will be explored in this study.

## Impact on Financial Status

The impact on financial status has been identified as when the caregiver feels that the additional expense incurred, such as purchasing of medical care, medical supplies, and services, has placed a financial strain on the family. This may be another type of burden for the caregiver. As the older person's degree of impairment increases, the costs of services also increases (Day, 1985). Many families cannot afford to purchase support services for even a short period of time in order to offer some relief. Support services are very expensive. Also the purchasing of medical care, medical supplies, and medications is costly.

Day (1985) states that "the cash value of services performed by families far exceeds the combined cost of government and professional services to both elderly living in the community and those living in institutions" (p. 7). Day (1985) also cited a 1984 report from the Federal Council On Aging that estimated that between 30 to 40 percent of households providing care to a disabled elderly person were providing service equivalent to a full-time job. Day (1985) reported on another study, done in 1976 by the General Accounting Office, that shows the costs of services provided by a family or friend for a moderately impaired elderly adult was $181 per month. According to Snyder and Keefe (1985), many caregivers, which are often elderly women, are living on fixed incomes. As a result, they do not have the financial resources to use a wide variety of programs if even available in their communities.

Some caregivers have to resign from jobs in order to care for an elderly person. Brody (1985) states, "that twenty-eight percent of our sample of non-working women had quit their jobs because of their elderly mothers' needs for care" (p. 25). Archbold (1980) states, "that funding became an issue for all of the families" (p.80) in a study done by her. Families have to juggle finances in order to keep the family solvent. Sometimes caregivers have to assume an additional job in order to meet the added expenses incurred from the care of an elderly person in the home. In regard to spouse caregivers, Cantor (1983) cites data that the greatest strain spouses reported was financial strain along with physical strain.

In summary, financial burden can be described as the additional expenses incurred, such as purchasing of medical care, medical supplies and medications, as when the caregiver has to assume an additional job in order to meet expenses, or when a caregiver must resign from employment in order to assume the care of the elderly person. Financial impact in this study will be defined as when the caregiver feels that the additional expenses incurred, such as purchasing of medical care, medical supplies, and services has placed financial strain on the family. The purpose of this study will be to identify if the caregiver perceives an impact on his/her financial situation in performing the caregiving role in relation to the caregiver's sex, socioeconomic status, and relationship to the elderly person.

### Impact From Family Abandonment

An impact from family abandonment was identified as when the caregiver feels that family members do not assist with the elderly person's care. Factors that can be identified as impacts on family relationships are when the caregiver believes that other family members have left her/him alone to care for an elderly family member, or family members don't understand the difficulty in caring for someone.

Resentment among siblings (children of the elderly) may develop because the caregiver feels that he/she is giving all of the care to the impaired elderly parent with no support from other siblings. Another factor for resentment is that the caregiver feels that another sibling, who is not caring for the parent, is considered the favorite by the parent. A theme Hartford and Parsons (1982) found in working with small groups of caregivers was that "members felt bombarded by helpful suggestions from other relatives" (p. 395). Other group members felt resentment that other relatives did not offer or provide more help. Chenoweth and Spencer (1986) found that some primary caregivers were resented by others in the families who denied the problems of the elderly person. Scott, Roberto and Hutton (1986) documented that a high degree of support was reported by their families and a low level of emotional upset resulted from family support efforts.

Spouse-caregivers may have a different perspective of family relationships than parent-caregivers. The spouse-caregiver may have less sense of family support in that they are alone with the ill person. Other family members may show disapproval at the type of care being given by the spouse (Gwyther & Matteson, 1983). The relationship with the spouse's partner has changed because of the disability. Spouses may feel that they have lost their best friend. The husband or wife may be affected negatively by the relationship with his/her partner once he/she is in the caregiving role. The spouse-caregiver may also be affected by the attitudes and lack of support from other family members. Johnson (1983) found that male caregivers, when compared with female caregivers, had more frequent contact with children, relatives, and friends.

In summary, family resentment can develop either from lack of reciprocation in the caregiving role and/or lack of support in providing care to the elderly person, or criticism from other family members regarding care of the chronically ill elderly person. There will be a focus in the study on whether the caregiver perceives if family members are supportive in providing care, or if the family has abandoned him/her in providing care to the elderly person. Again, the affects of sex, socioeconomic status, and relationship of the caregiver to the elderly person will be analyzed in relation to perceptions of impact on family relationships.

## Summary

The concepts - impact on caregiver's schedule, impact on health status, financial concerns, and the affect from family abandonment - have been presented as burdens of caregiving. Therefore, the perceived burdens of the caregiver will be defined as the way the caregiver believes the experiences of caring for an elderly impaired person are affecting and/or impacting certain aspects of his/her life. In the previous pages the areas that were discussed were: (1) impact on schedule; (2) impact on health status; (3) impact on financial status; and (4) impact from family abandonment. These four areas will be explored in the study.

In summary, the concept of caregiver, burdens, and elderly person will be identified. The caregiver of an elderly person may be identified as a woman in her 40's or 50's with a husband and children, or she may be a grandmother. The average age of a spouse caregiver is 66, with more than 30 percent being over age 74 (Day, 1985). The responsibilities of the caregiver involved in providing care for the elderly can be shopping and running errands, transporting the elderly person to a physician's office, arranging appointments, money management of the elderly person's finances, laundry, managing daily the problems of incontinence, both bowel and bladder, managing constipation, feeding, meal planning, bathing, transferring the person from bed to chair or bed to commode chair, and lastly, making decisions regarding symptoms that should be reported to the physician. These tasks can extend over 24 hours and also may include handling aggressive changes in behavior of the elder person. Added to the responsibilities mentioned, the caregiver must manage his/her own household.

The elderly person (the recipient of care) may be identified as stated in Beck and Phillip's article, "Abuse of the Elderly" (1983), "frail when because of mental or physical limitations, they no longer can independently meet all of their daily needs" (p. 97). Feller (1983) states that "the need for the help of another person increases sharply with age, especially among the elderly. Fewer than 1 in 10 who are 65-74 years of age need help, compared with 4 in 10 who are 85 years of age or over" (p. 1). The rate of needing help in at least one basic physical activity (walking, going outside, bathing, dressing, toileting, getting in and out of bed or chair, eating) was higher in the persons in the older age group 65 -74. The rate of needing help more than doubled in the 85+ group.
These impaired elderly require social services, nursing care, nutritional aid, and personal aid which are often provided by family members such as adult children or spouses. The purpose of this study is to ascertain if caregivers believe that there is an impact on their schedules, health status, financial status or feelings of family abandonment when they provide care for an elderly impaired person. In Figure 1, the study design for the

original research of Given and Given (1985) from which this sample was taken, is presented. From the design, a small model (Figure 2) is presented showing the concepts for this study.

In Chapter 2, the concepts of perceived burdens, caregiver, and elderly person have been developed. The review of literature of each concept will be presented in Chapter 3.

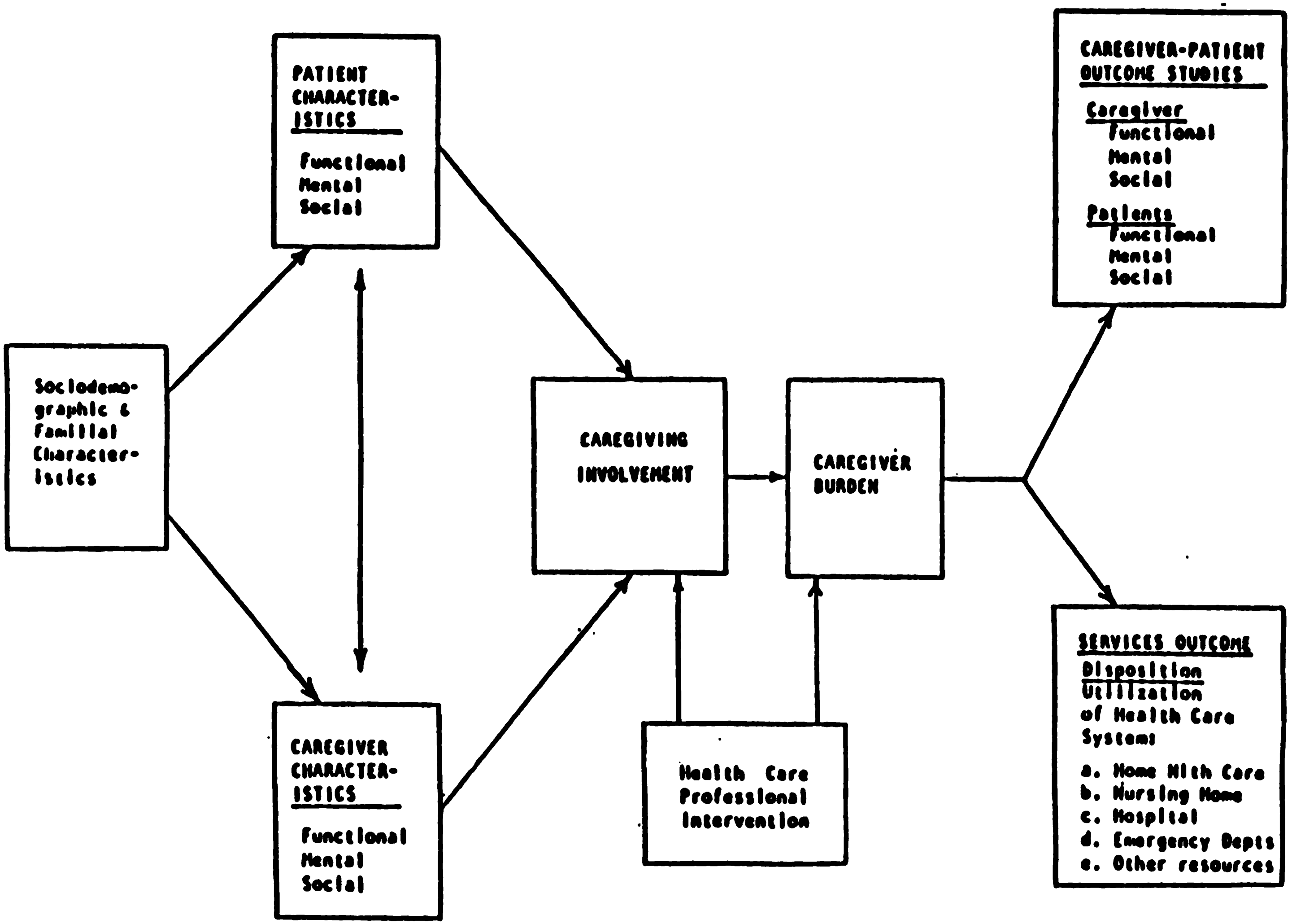


Figure 1: Caregiver Model
From "Caregiver Responses to Managing Elderly Patients at Home"
by B. Given and C. Given, 1985.

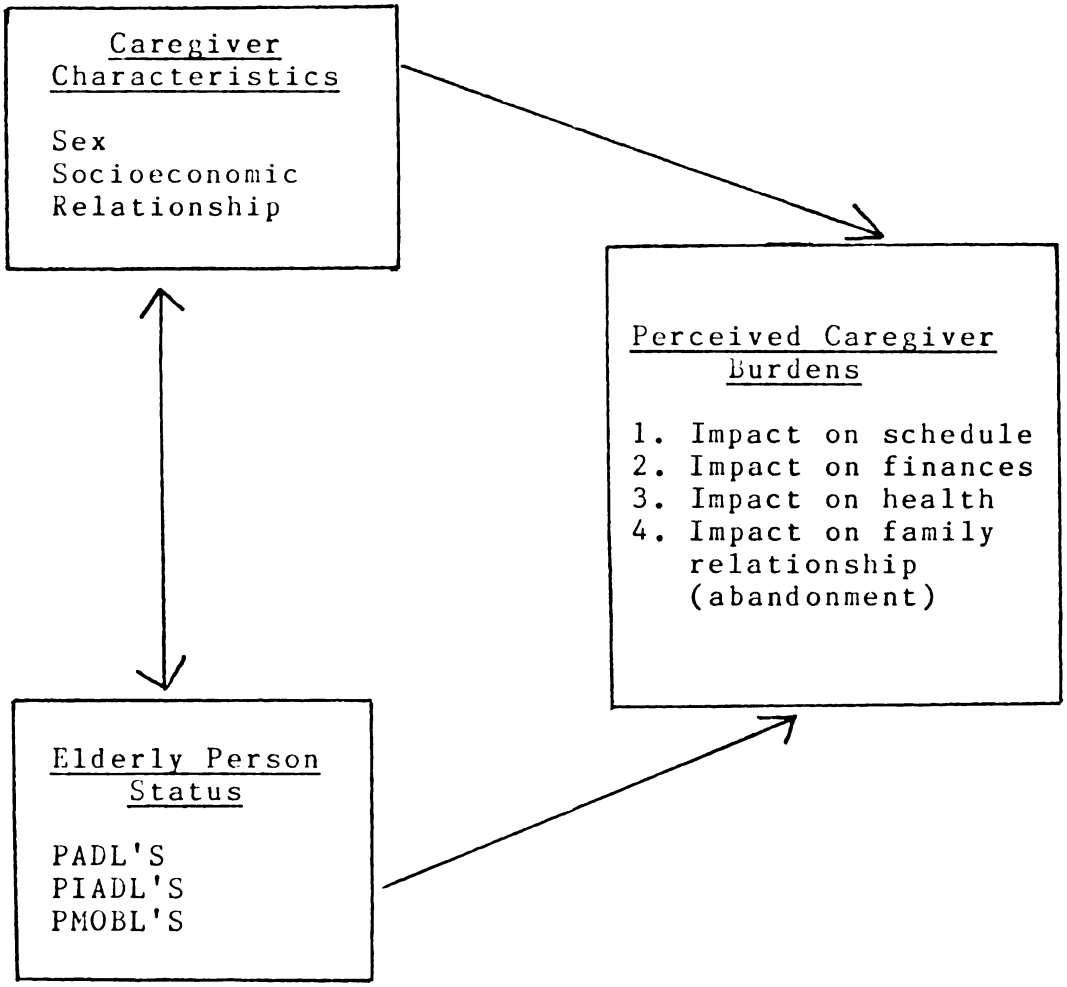


Figure 2: Model for Caregiver Study Involving Caregiver Characteristics and Perceived Burdens.

# Chapter III

# REVIEW OF LITERATURE

## Overview

The purpose of Chapter III is to demonstrate through a literature review, the studies, research, or contributions of others on the understanding of the impact of providing care to an elderly impaired person. The concepts of caregiver, elderly person, and perceived burdens of caregiving will be addressed in this chapter. Studies in which caregiver characteristics, such as sex, socioeconomic status, and relationship of the caregiver to the elderly person will be presented. Some studies in which there are differences in the impact on the caregiver's life as a result of these selected characteristics will be given. Next, there will be research presented on the elderly person's functional status and whether the impairment of the elderly person has an effect on the impact on the life of the individual providing care to the elderly individual. The four dimensions of possible impact on a person providing care to an elderly impaired person will be described in the final section. The dimensions are: (1) impact on schedule; (2) impact on health status; (3) impact on finances; and (4) impact on family relationships in the form of abandonment. The problem statement for this study is: "For elderly patients with similar functionalstatus, how are selected caregiver characteristics related to perception of burden?".

## Caregiver

In this section, a literature review of caregiver will be developed. The caregiver characteristics of sex, socioeconomic status, and relationship of caregiver to the impaired person will be described. There will not be a separation of the characteristics into sub-concepts because the studies presented either present several characteristics together or just present one characteristic and its possible affect on the caregiver's life.

The caregiver is identified as a spouse, an adult child, or other family member, who self acknowledged that he/she is caring for a debilitated elderly person. Archbold (1982) did an exploratory study (through interviews and observations) of 30 Caucasian women, because she felt through the contributions of others such as Brody (1981), that caregiving is considered women's work. "The responsibility falls to the wife, the daughter, or daughter-in-law of the ill person to provide the care and support services necessary for him/her to remain at home" (Archbold, 1982, p. 6). The average age of the women, in the study, doing parent-caring, was 53 years.

In Snyder and Keefe's (1985) one-point-in-time survey of 117 caregivers, the females outnumbered the males by two to one, and the average age of the caregivers was 60 (spouses were the predominant caregivers in the study). George and Gwyther (1986) also demonstrated, through a one-point-in-time study on caregivers, that 71% of the caregivers were women, and the average age of the caregivers was 57. They stated that most of the caregivers were the spouses or adult children of the impaired elderly person. George and Gwyther (1986) noted that the caregiver sample was not representative of the general adult population of North Carolina because selection of the caregivers was not a random process.

The age of the caregiver and the sex of the caregiver is supported by Hawranik (1985) in her exploratory study (one-point-in-time questionnaire). In her sample (60 caregivers), the majority of caregivers were daughters, whereas in Snyder and Keefe's (1985) sample, the spouses comprised 3/4 of all the caregivers. In several studies, (Snyder & Keefe, 1985; George & Gwyther, 1986; and Hawranik, 1985) the female caregivers outnumbered the male caregivers. The average caregiver's age in Hawranik's (1985) study was 52, slightly less than in Snyder and Keefe (1985) and George and Gwyther, (1986).

Cantor (1983) graphically depicted the sociodemographic characteristics of the caregivers in her exploratory study. In the total sample of caregivers (N = 111), most were females, but the majority of spouse caregivers were male. Most of the adult child caregivers were between 40-59 years of age (57.5%), and almost half of the spouse-caregivers were over 75 years (48.6%). As demonstrated also by Snyder and Keefe (1985), most spouse caregivers are older than adult-child caregivers. Cantor (1983) referred to the "generation in the middle" when discussing adult-child caregivers, who have competing demands from their families, work, and the frail elderly person. Another factor shown by Cantor (1983) was that 34.2% of caregivers were high school graduates, and 33% completed twelfth grade or less. The sociodemographic characteristics in Cantor's (1983) study were the most clearly presented, but the sample does not appear to be representative of the general population because it was geared to the caregivers of the elderly with marginal income, and the population for the study consisted of clients from one major homemaker service in New York City.

In Johnson's (1983) study on family supports for post-hospitalized individuals aged 65 years and older, the support was provided mainly by spouses. In other words, the support was mainly given by an age peer rather than a younger person. The principle of substitution operated in which each family member is available in serial order rather than the family as a unit providing support. Johnson (1983) supports Archbold's (1982) statement that "one family member is usually identified as the caregiver. In general, this responsibility falls to the <u>spouse</u>, where one exists, or to a <u>daughter</u> or <u>daughter-in-law</u>" (p.12).

Johnson (1983) further discusses the fact that if the elderly person is seriously incapacitated, bedfast, or housebound, it is the spouse who most frequently provides the care. The presence of a spouse, rather than the offspring is a major factor in preventing institutionalization of an impaired elderly person. Johnson's (1983) study supported the "principle of substitution", that the person available to an impaired elderly person provides the care. "Among 167 families, 45% identified the spouse as the primary caregiver in contrast to 39% who identified a child" (Johnson, 1983, p. 378). In the remaining cases, 8% had a sibling as a caregiver, and another 8% had a niece, nephew, or grandchild. Among those patients who were married, a spouse was identified as the primary caregiver; among the widowed, a child was identified. "Among the married with children, the spouse rather than a child was identified as the major caregiver in 90% of the cases" (Johnson, 1983, p. 379). In the situation of the widowed or divorced with children, who had a surviving sibling, a child was the major caregiver in 89% of the cases. When childless and unmarried older people had to turn to siblings, or more distant relatives, such as a niece, a nephew, or cousin, these relatives rarely provided supports such as shopping, housekeeping, or personal care, as extensively as spouses or child caregivers did. Formal supports were secured more often. The more distant relatives usually arranged for a community service for the patient. Johnson and Catalano (1983) found that a spouse as a caregiver was a more stable arrangement over a 8-month period of time (two-step longitudinal study) unless the spouses's health declined. (Of those who continued to provide some level of care or increase in care over a period of time, there were 62% spouses and 27% children.) In Johnson's (1983) study, the elderly person was not always living in the same home as the caregiver.

In thinking of the fact that females are usually the caregivers, Zarit, Todd, and Zarit (1986) found that "caregiving is usually defined as a woman's role, an expansion of the traditional responsibilities of a wife or daughter" (p. 260). Brody (1985) presented the same information, that caregiving is traditionally and culturally a woman's role. Crossman, London, Barry (1981) also stated that "women have traditionally been the primary caregivers in our society" (p. 464). Brody (1981) agreed that older people in need of help look to daughters, rather than sons for assistance. This reflects the "cultural assignment of gender appropriate roles" (Brody, 1981, p. 474). Sons handle financial arrangements and home repairs which is expected of them. Brody (1985) found in a survey of 165 middle generation women (34-62), that they were more likely to expect working married daughters than working married sons to adjust their work schedules for parent care. In fact, the three generations (Generation 1: 57-91 years; Generation 2: 34-62 years; and Generation 3: 17-44 years) expected working married daughters to adjust schedules more so than working married sons in order to provide care, (Generation 1: 55% for daughters to adjust, 40% for sons to adjust; Generation 2: 38% for daughters to adjust, 24% for sons to adjust; Generation 3: 42% for daughters to adjust, 31% for sons to adjust). So it appears, that even though values are changing and there is more equality among sexes, there are still traditional values of females being caregivers more so than males as caregivers.

In many studies (Hawranik, 1985; Johnson & Catalano, 1983; Montgomery, Gonyea & Hooymann, 1985; Snyder & Keefe, 1985; Worcester & Quayhagen, 1983; George & Gwyther, 1986; Zarit, Reeves & Bach-Peterson, 1980; Scott, Roberto & Hutton, 1986; Brody, Johnson & Fulcomer, 1984; and Fengler & Goodrich, 1979), it is demonstrated that females predominate as caregivers. If a male is a caregiver it is usually because he is a spouse to a disabled wife. Male caregivers have been compared to female caregivers in a few studies (Fitting, Robins, Lucas, & Eastham, 1986; Zarit, Todd & Zarit, 1986; Snyder & Keefe, 1985; and Johnson, 1983). Findings and descriptions from these studies will be presented under the concept of burdens.

In regards to the socioeconomic status of the caregiver, the levels of income for the majority of caregivers (studies in which income was presented) was approximately between $18,000 to $30,000 per year (Zarit, et al., 1986; Scott, Roberto & Hutton et al., 1986; Chenoweth & Spencer, 1986; and Montgomery et al., 1985). Cantor (1983) did not present income, but 63.9% of the primary caregivers were considered to be in the working and lower classes, which was computed on spouse's education and occupation of female respondents, so Cantor's (1983) socioeconomic status cannot be compared to other studies (same scale not used). Chenoweth and Spencer (1986) stated "that their sample (N=222) was biased toward a well educated, middle class, white population" (p. 272). The questionnaire was long and maybe only the more literate returned it. Montgomery et al.

(1985) states that the sample was so small and restricted (predominant Caucasian [89%]), the results should be generalized with caution.

The education level of caregivers was described in several studies (George & Gwyther, 1986; Cantor, 1983; Zarit et al., 1986; and Scott et al., 1986). In Cantor's (1983) sample of caregiver (N=111), 33.3% had an educational level of 12th grade or less, and 34.2% were high school graduates. The spouses (same age peer as care-recipient) had the largest percentage of 12th grade or less. In studies of George and Gwyther (1986), Zarit et al., (1986), and Scott et al. (1986), the caregivers had a level of education of 13 years or more. Scott et al. (1986) studied a sample that was very small (N-21) and mainly women. Chenoweth and Spencer's (1986) sample of 288, were mostly female with 63% having some college or graduate school education. As mentioned earlier, their sample was biased toward a well educated, middle-class, white population. In this study, the feeling of the impact from caregiving will be explored as to the caregiver's educational level and income level.

In summary, caregivers to elderly impaired persons are predominately female, who are middle-aged (45-60 years) if they are adult-children. The spouse caregivers tend to be 60 years or older. If there are male caregivers, they are usually spouses of the impaired individuals. Females are still traditionally considered to be the caregivers. Values might be changing because of women working, but according to

Brody's (1985) study of three generations of women, it is expected that female children (married) adjust their work schedule to provide parent-care rather than a working son. The responsibility of caregiving to the elderly individual is in serial order, i.e., spouse first; if widowed, the adult-child; if no children or spouse, then other family members.

Some of the samples in the studies of caregivers have been large, so they may possibly be generalized to the population even though they are not random samples. One glaring limit to the studies presented are that most were involving predominately Caucasian participants, biased towards a middle class population (Fitting et al., 1986; Worcester & Quayhagen, 1983; Johnson, 1983; Zarit et al., 1980; Johnson & Catalano, 1983; Archbold, 1982; George & Gwyther, 1986; Chenoweth & Spencer, 1986; Zarit et al., 1986; Cantor, 1983; and Snyder & Keefe, 1985). There needs to be more research on caregivers of various ages, sex, socioeconomic status, and relationship as to how providing care to an elderly disabled person impacts their lives. The purpose of this study is to explore the impact on the lives of caregivers as affected by sex, income, education, and relationship to the elderly person.

## Elderly Person

In this section, a literature review of the elderly person will be developed in terms of functional health status. The functional status of the elderly individual might have an affect on the feelings of impact by the caregiver while he/she is providing care. A few studies will be presented, demonstrating that there is an impact on caregivers as the result of degree of the elderly person's impairment. The elderly person can be defined as an elderly recipient of care, who is frail, and because of mental and/or physical incapacities can no longer live independently. Impaired elderly persons require nursing care, personal care, and social services which are often provided by a family member (most likely an adult daughter if there is no spouse).

"At all ages, some adults need help, but as age increases, the percentage needing help increases geometrically, almost doubling with each succeeding decade between 45 and 80 and then nearly tripling" (Fillenbaum, 1985, p. 688). Forty-four percent of community residents over the age of 85 were found to need help (Fillenbaum, 1985). If these elderly individuals are to remain in the community, the support of family, friends, and community agencies is essential. "The need for help of another person increases sharply with age, especially among the elderly. Fewer than 1 in 10 who are 65-74 years of age needed help, compared with 4 in 10 who are 85 years or over" (Feller, 1983, p. 1). The rate of needing help with one basic physical activity (walking, going outside, bathing, dressing, using the toilet, getting in or out of bed or chair, eating, is "52.6 per 1,000 people 65-74 years of age, and 157.0 per 1000 people 75 years of age and over" (Feller, 1983, p. 3). The rate for people 85 years plus was 348.4

per 1000. The rate per 1,000 people who had trouble controlling bowel movements or urination increased with age: 17.3 per 1000 (65-74 years of age) and 46.7 per 1000 people 75 years of age and over. The rate for those staying in bed per 1000, (which means possibly turning, lifting, and transferring) was 11.3 per 1000 for those between 65-74 years of age and 30.4 per 1000 for those 75 years and over (Feller, 1983). According to Worcester and Quayhagen's (1983) study, the leading causes of illness for those over 60 were: hypertension, heart problems, diabetes mellitus, arthritis, cerebral vascular accident, and senility. Depending on the severity of the illness, the health problems of an elderly person can contribute to the determination of functional status of the individual. At present, 5% of older persons are in institutions, but the proportions rises with age, particularly if there is no community or family support.

Fillenbaum (1985) graphically documents through a screening of 3 surveys (N=997, N=1530, and N=1609) that independent functioning declines with increase in age. The decline tends to occur in the 80-84 year old age group. An example is: Can you get to places out of walking distance without help? The results were: 87% (N=223) of 65-year olds could; 76% (N=188) of the 70-year olds could; 67% (N=113) of the 75-year olds could; 38% (N= 53) of the 80-year olds could; and 14% (N=36) of the 85-year olds could. The results for men and women were about the same, but a larger proportion of men is capable of going places without aid. The author indicated that this was because the women were somewhat older in the surveys than the men.

In considering the importance of family support for the impaired elderly person, Garner and Mercer (1982), in presenting a portrait of the current nursing home population, state, "a third of the residents of long-term care facilities have no relatives. Those who have families were institutionalized as a last resort" (p. 186). Families had exhausted alternatives, and had endured personal economic stress in caring for an impaired relative. Getzel (1982) states that "although the presence of a spouse may forestall or avoid institutionalization, it may also be at considerable cost to the caregiver" (p. 516). Shanas (1979) had supported the fact that persons without close families (those very old who are widowed or never married) are most likely to be institutionalized. The majority of the sick and frail elderly in 1975 (a national probability study of those person 65 years and older) were not institutionalized but living in their own homes or with family members.

The caregiver's impact of providing care to an elderly impaired person is the focus of this study. Several studies will be described in which the impairment of the elderly person might have an affect on feelings of impact on the life of the caregiver.

George and Gwyther (1986) surveyed four dimensions of well-being of caregivers (physical health, mental health, finances, and social activities). Three well-being measures were significantly correlated, though modest in strength (i.e. r =.20) with severity of patient's symptoms. The three measures - lower self-rated health, a higher-level of stress symptoms, and less time the caregiver spends relaxing, were associated with more serious patient symptoms. The patient's symptoms were not documented in this study. (The patients were mainly diagnosed with Alzheimer's Disease.)

In Worcester and Quayhagen's (1983) study, in which they were to identify specific variables which could predict caregiver's satisfaction, the psychological and physical limitations of the elderly person were included (11% of the 19 persons had cognitive dysfunction and 89% were dependent due to stroke, cardiac problems, and diabetes). Psychological problems of the elderly person had the strongest negative influence on caregiver satisfaction (Path coefficient = -.292) while medical problems of the elderly person showed less influence (Path coefficient = -.007 $p<.05$).

Hawranik (1985) reported that from a one time interview of 60 elderly persons (in rural Manitoba) and their caregivers, that the "variables of functional impairment and cognitive impairment on the part of the parent (the elderly person) did not have any influence on caregiver's burden" (p. 21). The Index of Incapacity was utilized to measure the functional status of the elderly person. The ones with organic brain syndrome could not participate, so cognitive impairment was probably minimal.

Sushil's (1985) study disagrees with Hawranik (1985), Worcester and Quayhagen (1983), and George and Gwyther (1986). Results of this study (only an abstract was documented) "indicated that caregivers of chronically physically ill patients experienced significantly greater sense of social, physical, and overall burden than did caregivers of patients suffering from dementia" (p. 59).

Snyder and Keefe (1985) report that a statistically significant relationship was found between the level of disability of the disabled adult (ADL's measured on Multiple Sclerosis group, a stroke group, and an Alzheimer's group, N=117) and the presence of health problems in the caregiver (r =.13 p<10). The correlation is weak, but shows the impairment does have an effect on the likelihood of the caregiver reporting health problems.

In a longitudinal study by Johnson and Catalano (1983), (over 8 months in San Francisco with 167 families), the Oars Activities of Daily Living was used to examine level of functioning of the elderly person. In the dependent group of elderly recipients of care (needed help in more than two activities at a time), the caregivers experienced significantly more strain (48% compared to 11% of caregivers of the independent group).

Poulshock, Gary, and Deimling (1984) studied 614 families on how the effects of different types of elder recipient's impairment impacted certain areas of the caregiver's lives. The physical impairment of the elderly person was measured by using Activities of Daily Living, such as bathing, dressing, toileting. Mental impairment was divided into three dimensions of sociability, disruptive behavior, and cognitive incapacity. The strongest correlation (r = .63) was between the disruptive behavior exhibited by the elders, and negative impact on elder-caregiver/caregiver-family relationships (such as elder has negatively affected caregiver's relationship with family members). This finding disagrees with Zarit et al. (1980), who documented that there was little correlation between mental impairment of the elderly recipient and caregiver burden. The Fitting et al. (1986) survey of 54 spouse caregivers also documented that there was no association between severity of care recipient's mental functioning and caregiver burden. The burden scale of Zarit et al. (1980) was more undimensional and might have been measured differently. In continuing with the study reported by Poulshock et al. (1984), the ADL impairment of the elderly person was more highly correlated with caregiver's social activity restrictions (r = .45). This correlation still is not as strong as the negative impact on family relationships from the mental impairment of the elderly person.

Finally, Hooyman, Gonyea, and Montgomery (1985) studied 80 caregivers in regards to perception of burden as affected by the termination or continuation of in-home chore services. This study is mentioned because the perception of burden (a 14 item burden scale, 5 point Likert-type response) of the caregiver was strongly correlated with the performance of personal care tasks, such as bathing, feeding, and toileting. An example of a question is that the respondent was asked if his/her health had "become a lot better", "become a little better", "remained the same", "became a little worse", or "became a lot worse" than it was a year ago. The measurement of activities of daily living (ADL's) was used for the elderly person's functional status.

In summary, there is agreement that the impaired elderly person is generally given support by his/her family. If the elderly individuals are to remain in the community, the support of family, friends, and community agencies is essential (Fillenbaum, 1985). Both Fillenbaun (1985) and Feller (1983) document that the percentage of people needing help increases sharply with age, especially over the age of 80. An example is that of those needing help for physical activity, such as walking, going outside, bathing: 52.6 per 1000 people 65-74 years of age; 157.0 per 1000 for people 75 years and over; 348.8 per 1000 for those 85 years and over.

The fact that people become older and need more assistance, means that family member (if any) will most likely be giving the assistance. Also, studies have been done on whether various types or degrees of impairment (mental or physical) has an affect on how the caregiver perceives or feels an impact on his/her life. The studies are not longitudinal. Also, each study measures a different type of impairment, different types of burden or impact, or uses global burden scales. In other words, it is difficult to compare one study with another. George and Gwyther

(1986) found a modest correlation between patient's severity of symptoms (not listed) and caregiver well-being; Worcester and Quayhagen (1983) showed psychological problems had negative impact on caregiver's satisfaction but there was less influence on caregiver's satisfaction from medical problems. Sushil (1985) documented that those with chronically physical ill problems lead to more perceived burden by caregiver than those caregivers caring for a person suffering from dementia; Hawranik (1985) reported that the degree of impairment of the elderly person (did not use those with cognitive impairment) had no effect on caregiver's feelings of impact; Snyder and Keefe (1985) found a statistically significant relationship between level of disability of the elderly person and health problems of the caregivers; Poulshock et al. (1984) being more specific found a strong correlation with negative caregiver/family caregiver relationships (elder has affected caregiver relationship with family members) and disruptive behavior of the elderly person; ADL impairment of the elderly person restricted the caregiver's social activities; and Hooyman et al. (1985) reported that perception of burden was strongly correlated with the personal tasks (e.g. bathing, dressing, feeding) done by the caregiver for the elderly recipient of care.

From the studies mentioned, there is not a definite measurement of impairment or one specific type of burden that is either measured the same or studied consistently. In this study, the elderly person's functional health status will be controlled, since there is variation in individual elders functional status in order to study the perception or feelings of impact by the caregiver on his/her life.

## Perceived Burden

In this section, several burden scales used in measuring the impact of caregiving will be presented. Then studies which used scales in the global sense rather than separating the various dimensions of burden will be discussed. In the last part of this section, studies will be described regarding the various dimensions of impact such as schedule, health, finances, and family relationships.

"The term 'caregiver burdens' now is mainly used to refer to the physical, psychological or emotional, social, and financial problems that can be experienced by family members caring for impaired older adults" (George & Gwyther, 1986, p. 253). According to Archbold (1982), the understanding of the consequences of prolonged caregiving to a severely functionally impaired family member is just beginning. Family caregiving may last for years. "Often it begins when the caregiver - either wife or daughter - is herself old or nearing old age" (Archbold, 1982, p. 13). Physical and psychological burdens are placed on people with decreasing strength and energy. Giving care to an impaired elderly person can involve continuous 24 hour care, such as bathing, dressing, feeding, handling bowel and bladder incontinency, giving medication, turning, lifting, and supervision.

In several studies, the strain of caregiving has been expressed in a global sense (Fitting et al., 1986; Pratt et al., 1985; Zarit et al., 1986; Zarit et al., 1980; Johnson & Catalano (1983); and Scott et al., 1986). The Zarit (22-item) Burden Scale (1980) was used in the studies mentioned, except for Johnson and Catalano's (1983) study, in which an interview of open-ended questions on how providing care to an impaired elderly person affected their daily lives was used. The Zarit Burden Scale includes items relative to caregiver's feelings about his/her health, psychological well-being, finances, social life and relationship with a demented relative as a result of providing care to that individual.

Robinson (1983) composed a screening instrument for caregiver's strain in which there were 13 items (questions) on confinement, emotional adjustment, physical and financial strain of the caregiver. (The Chronbach alpha was . 86.) Montgomery, Gonyea, and Hooyman (1985) developed a 9-item inventory for objective burden (e.g. amount of privacy you have available, amount of money you have available) and a 13-item inventory scale adapted from the 29-item inventory of Zarit et al. (1980), for subjective burden (e.g., I feel it is painful to watch my relative age). Worcester and Quayhagen (1983) designed a caregiver's satisfaction scale which consisted of a global rating as did Zarit's Burden Scale and Robinson's caregiver strain questionnaire (Caregiver Strain Index).

The instruments or questionnaires such as Zarit's Burden Scale, Robinson's Caregiver Strain Index, and Worcester and Quayhagen's Caregiver Satisfaction Scale, measure over-all stressors of caregiving. Strain and burden are two terms that should not be used interchangeably, but there could be the assumption that if a caregiver feels strain, then he/she perceives caregiving to be a burden or perceives caregiving to have an impact on some dimension of his/her life. The physical, social, and emotional dimensions are covered in Zarit's, Robinson's and Worcester and Quayhagen's scales, but each dimension is not analyzed separately.

The various perceived areas of impact on caregivers' lives will be developed in this study, using four dimensions. Before the four dimensions of impact are presented, (impact on schedule, impact on financial status, impact on health status, and impact on family relationships in the form of abandonment), there will be some discussion on global caregiver burden as found in the above mentioned studies. Some of the studies were given in the section on the concept of the elderly person, but they are repeated here to show the global dimension of some of the burden scales and the differences in measuring burden from one study to another. Also, some studies will be presented that include characteristics of the caregiver and if the characteristics show an effect on the impact of caregiving.

In focusing on over-all caregiver burden, Zarit et al. (1980) found that feelings of burden by the caregivers were not related to behavior impairment or functional impairment of the care-recipient (the impaired elderly person). In another study by Zarit et al. (1986), a longitudinal study on caregivers of demented patients was done two years after the first interview. It was found that the burden scores decreased by the time of the two year follow-up. The researchers concluded that by the end of two years, the caregivers were managing problems better and coping more effectively. Scott (1986) and Fitting et al. (1986) also documented that there was no association between severity of care-recipient's mental functioning and caregiver burdens. Fitting et al. (1986) did find that in controlling for sex and age, increasing severity of illness of care-receiver was associated with higher perceived burden in younger wives and older husbands. The conclusions here were that younger wives have other demands, such as children in college, or jobs, and that the younger wives did not expect to be a caregiver at this time of their lives. The older husbands, because of their ages, may have been suffering from chronic illness themselves, thus, found caring for a wife to be very difficult.

Johnson and Catalano (1983) and Worcester and Quayhagen (1983) differed from Zarit et al. (1980, 1986), Scott et al. (1986), and Fitting et al. (1986). Johnson and Catalano (1983) reported that the more impaired (needing help in two or more activities of the Oars Activities of Daily Living Scale) the care-recipient (elderly person) the more strain on the caregiver. Worcester and Quayhagen (1983) reported that caregiver satisfaction decreased as psychological problems of the care-recipient increased. They studied 19 current caregivers and 29 past caregivers. These authors concluded that mental deterioration was the main reason for nursing home admission because of caregiver dissatisfaction. The differences in the studies could be related to the methods or instruments used to obtain information on caregiver strain. Through interviews, Johnson and Catalano (1983) used an open-ended questions format (questions not provided) on the effects of the elderly person's illness, and the need for providing care had on the caregiver's daily life. Worcester and Quayhagen (1983) used the Caregiver's Satisfaction Scale which might not measure strain, but gave an indication that caregiving can be stressful or cause negative consequences for the caregiver. Zarit et al. (1980), Zarit (1986), Scott et al. (1986), and Fitting et al. (1986) used the same instrument, the Zarit Burden Scale of 22 items. Johnson and Quayhagen (1983) might have received more in-depth answers from the caregivers because of the open-ended questions, thus, causing a difference in results from Zarit et al. (1980) and others.

A few studies have been done in which characteristics of the caregiver have been explored. The caregiver characteristics, such as sex, income, and education and the relationship of the caregiver to the impaired elderly person, have been studied as to the effect on caregiver burden. Fitting et al. (1986) found in controlling for sex and age, the severity of illness of the elderly person was associated with higher perceived burden in younger wives and older husbands. Worcester and Quayhagen (1983) in using a Caregiver Satisfaction Scale with 19 current caregivers and 29 past caregivers, found that age of the caregiver had the strongest positive influence on stated satisfaction (path coefficient = .407). Robinson (1983) reported that caregiver strain was not significantly related to sex of caregiver, to the relationship of the caregiver to the impaired older person, to health status of the caregiver, or to living arrangement either living with older persons or not living with elderly person; but employment of the caregiver had significant correlation with caregivers strain scores. Zarit et al. (1980) reported no differences in feeling of burden reported by daughters compared to spouses providing care. In contrast, Cantor (1983) comprehensively studied the degree of strain experienced by type of caregiver (spouse, child, relative, friend) and found that the closer the bond, the greater the amount of strain. "Spouses were the group at greater risk, followed by child, other relatives, and friends, and neighbors" (Cantor, 1983, p. 601). Spouses reported the greatest degree of emotional, physical, and financial strain.

George and Gwyther (1986) findings were compatible with Cantor (1983) in that spouse caregivers exhibited lower levels of well-being than adult-child caregivers or other relatives (study included indicators of well-being in the dimensions of physical health, mental health, financial resources and social participation). Spouses reported more doctors visits and poorer self-rated health than the other two groups of caregivers (adult-child and other relative). Spouses also reported more stress symptoms, more likely to use psychotrophic medications, and reported lower levels of life satisfaction than the other two groups. Male and female caregivers were not differentiated, but the study was comprised of mainly women (71%). Zarit et al. (1986) focused no differences in degree of burden for husbands and wives providing care for demented spouses over a two year period. At time I, women caregivers showed a higher burden score than men at time I. At time II, the burden score for men and women were the same. Zarit et al. (1986) concluded that caregiver's ability to tolerate problems may increase as the disease progresses.

In contrast, Johnson (1983) found that husbands as caregivers experienced less strain (possibly because they seek help of formal providers more or have more frequent contact with children) than wives as caregivers. In a sense, the finding agrees with Zarit et al. (1986) in which female spouse caregivers showed a higher burden score than the male spouse caregivers in the first time contact with caregivers. Johnson's research was not longitudinal. Pratt, Schmall, Wright, and Cleland (1985) reported on a study of 240 caregivers of Alzheimer's Disease victims: "There were no significant differences in burden scores by caregiver's sex (t = .44, df = 225), income level F (5,207) = 1.92; or education level, F (7,201) = 1.25" (p. 29).

The characteristic of socioeconomic status of caregivers is mentioned in only a few studies as to the effect on caregiver's feelings of burden. Worcester and Quayhagen (1983) documented that lower income (does not give income levels) persons show slightly more satisfaction with the caregivers situation than those in a higher income (path coefficient = -.036 in inverse correlation).

In summary, many studies on the impact of caregiving to a chronically ill elderly person have involved scales which measure caregiver burden in a global sense. They include the psychological, physical, financial, and social impact of caregiving, but there is one global rating for the whole instrument. The Zarit Burden Scale of 22-29 items has been most often used. Robinson (1983) has developed a Caregiver Strain Index instrument as a screening measure for addressing burdens of caregiving. The Zarit Burden Scale is reliable, but the various dimensions of impact on caregivers lives (emotional, physical, social and financial) are not addressed separately or comprehensively by Zarit's scale.

In measuring burdens of caregiving, there may be different results as to the degree of impact of caregiving as a result of the relationship of the caregiver to the impaired person (spouse, adult-child or relative), the degree of functional impairment of the elderly person, and the sex, educational and financial status of the caregiver. There needs to be more comprehensive research on the impact of caregiving in the various dimensions of caregivers' lives and the caregivers' perception of impact on their lives. There also needs to be longitudinal studies involving the degree of burden over time. Lastly, more research is needed on the relationship of the caregiver to the impaired person, the degree of functional impairment of the elderly person, the sex, educational and income status of the caregiver and whether they affect the caregiver's perception of burden on various dimensions of their lives.

In this study, there will be a focus on the four dimensions of impact that caregivers may perceive caregiving has on their lives - (1) impact on schedule; (2) impact on health status; (3) impact on financial status; and (4) impact from family abandonment as affected by sex, educational status, income level, and relationship of the caregiver. In the remainder of this chapter the four dimensions will be divided into sub-concepts and studies will be reviewed involving each sub-concept. If studies were found regarding how certain caregiver characteristics affect the feelings of impact of caregivers, they will be presented.

### Impact on Schedule

"One frequent consequence of caregiving is social isolation" (Archbold, 1982, p. 13). This statement is the result of an exploratory study of 30 Caucasian women by Archbold in 1981. She found that some caregivers cannot leave the house to shop, and can never plan a vacation. In another study, in which Archbold (1980, 1982, 1982) interviewed six caregivers, the scheduling of prescribed regimens caused difficulties for the caregivers. If, for example, an elderly recipient needs to be exercised twice a day and needs assistance from another individual, the caregiver has to schedule daily activities around the exercise schedule. Rigid scheduling of daily activities became necessary for four of the caregivers. If the parents required large amounts of care (e.g. bathing, dressing, nursing, preparing meals, etc.) then the caregivers had to change their life-styles and their daily activities. Social activities had to be decreased, and spur-of-the-moment shopping became impossible for four of the caregivers. The recipients of care sometimes cannot be left alone, so this accentuates the problem. Relief time is not in the caregiver's control even if he/she has assistance from an agency.

Montgomery, Gonyea, and Hooyman (1985) found through interviewing 80 caregivers that "the tasks that confined the caregiver in terms of time schedules or geographic location were found to best predict objective burden" (p.25). Objective burdens were the concrete events and happenings from caregiving, (e.g. amount of time you have to yourself), while subjective burdens were the feelings and emotions expressed about the caregiving experience (e.g. I feel it is painful to watch my relative). This study will focus on the feelings or perceptions of the caregivers regarding the impact on their lives.

William-Schroeder (1984) in discussing family caregivers of Alzheimer's patients state, "most caregivers are so overly involved with the demented person that they find it difficult to have a life of their own" (p. 36). Barnes, Raskind, Scott, and Murphy (1981) documented, through audio-taping of a support group (9 women, 6 men) for families providing home care to Alzheimer's patients, that the major problem mentioned by all members was the great amount of time required to care for even a mildly impaired Alzheimer's patient at home. As the patient became progressively worse, caregivers were giving total care to the impaired person, and soon felt trapped by the time and effort required. Isolation was a problem faced by spouses. The affectional and sexual needs of the marriage were no longer met. It became more difficult for caregivers to initiate independent activities because of time required for daily care of the patients; friends decreased social visits as behavioral problems of the patient increased; and most spouses felt that they could not leave the patient alone, so they could not go out for socialization.

Chenoweth and Spencer (1986) corroborated with the findings of Barnes et al. (1981) by documenting that 60% of the caregivers said that the relatives' illness had affected their relationship with other people, particularly mentioning that friends no longer visited and that the caregivers had to give up jobs, leisure and volunteer activities. Couples frequently lost contact with other couples when the spouse was a caregiver. Scott et al. (1986) report that in an interview of 23 primary caregivers of Alzheimer's patients "the type of assistance from family that seemed most appreciated were visits and having persons stay with the patient so that the caregiver could take a trip, rest, run errands, or get out of the house for social activities (p. 348).

Johnson (1983) documented on impediments of caregiving as reported by spouse, offspring, and other relative caregivers. One of the highest percentage of complaints by adult-child caregivers was the affect that the parents' illness had on their social lives (53% of N=65). The activities required by the adult child for caregiving reduced his/her social contacts. "The major competing commitment of the spouse caregiver was his/her own poor health" (Johnson, 1983, p. 381); affect on social activities was not high for the spouse caregivers. The other-relative caregivers rated even lower than the spouse or adult-child caregiver in saying caregiving affected their social obligations or health.

Robinson (1983) in process of developing a Caregiver Strain Index also found that all 81 caregivers studied perceived the caregiving changed their life-style. The types of life-style changes such as "could not go on vacation", "had to turn down a job", "cannot go visiting", or "no privacy" was not specifically documented in the report from Robinson's study. The rating for the entire index (Caregiver Strain Index) was given rather than a score for a specific dimension.

Cantor's (1983) comprehensive study tends to disagree with Johnson's (1983) study regarding the impact on caregivers' lives as to relationship of the caregiver to the impaired elderly person (spouse, adult-child, other relative). Cantor did study specific areas of impact on caregivers' lives as time available to spend with children and other family members, opportunities to socialize with friends, time to do things you like (movies, hobbies), ability to keep job or function on job, opportunity to take vacations, and free time without responsibility. In half the items mentioned, the impact was more severe on the spouse (N = 37) than the adult-child caregiver (other relative caregivers were lower in all items of impact). Sixty percent of the adult children were employed and two-thirds were residing in separate households from the elderly person. The spouses lived with their impaired mate and only eleven percent worked. Therefore, they had potential for more strain regarding less opportunity to socialize. The only area of higher impact for the adult-child caregiver in comparison to the spouse caregiver was the impact on ability to keep a job or function on the job. The impact on social activities for the adult-child caregiver was not rated higher than the spouse caregiver as mentioned by Johnson (1983). The results of Cantor's (1983) study led her to suggest that the closer the bond (the relationship), the more stressful the caregiving role. George and Gwyther (1986) in using a satisfaction with social activity scale (caregivers subjective assessment of his/her satisfaction with frequency and quality of social activities) on 510 caregivers reported that the means for satisfaction with social activity for spouse and adult children caregivers were the same and lower for other caregivers (spouse 7.94, adult-child 7.94, other relative 8.77).

Isolation and loneliness were two of the most frequently mentioned problems of wife-caregivers, of disabled men, who scored low on life satisfaction scales in Fengler and Goodrich's (1979) study of 112 women caregivers. George and Gwyther (1986) also found that caregiver burden, relative to a random community sample of non-caregivers, was experienced mostly in areas of mental health and social participation. Caregivers appeared to be worse off than random sample of non-caregivers in social activities (e.g. phone contact with family and friends, times spent in hobbies, and satisfaction with social activities). Women comprised 71% of George and Gwyther's (1986) sample, (spouse caregivers and adult-child caregivers). Hartford and Parsons (1982) in an analysis of a small group (N8-10) of caregivers, found that feelings of entrapment were expressed. Crossman, London, and Barry (1981) corroborated the same findings of sense of isolation, both social and emotional.

In thinking of socioeconomic status, the only study found was Archbold (1980). She reported that care providers, those who actually perform the tasks of caregiving, are in the lower socioeconomic level. They definitely felt an impact on schedule because they had to follow a schedule in order to accomplish the tasks for the day. The care managers, those who supervised or managed services provided, were generally in the higher socioeconomic level and did not feel such an impact on schedules.

In summary, the caregiver must often follow a rigid schedule in order to accomplish the tasks of caregiving, thus limiting social participation, and spur-of-the-moment activities. Friends decrease their visits because of the elderly person's illness, the elderly person's behavior, or the caregiver is too busy to visit. The behavior of the elderly person can be embarrassing to the caregiver so he/she avoids taking the impaired person anywhere, or he/she no longer invites friends to visit.

The impact of caregiving in regards to the relationship of the caregiver to the impaired person has been studied slightly, such as the adult-child caregiver feels more impact on social activities as a result of caregiving than the spouse-caregiver does. Archbold's (1980) study showed a slight association between caregivers being in a lower socioeconomic class and impact on caregiver's schedule. The study only involved 30 people and specifics of impact on schedule and actual income levels were not studied. More studies need to be done on impact of providing care to an elderly person as a result of type of relationship to the caregiver, sex, and socioeconomic status of caregiver, and as a result of the functional impairment of the elderly person.

There is an impact on the schedule of caregivers, but there needs to be additional research on whether the caregiver perceives an influence on his/her freedom, or whether there is an actual impact on his/her freedom. Also, there needs to be a comprehensive study in the actual strains perceived by the caregiver in the dimension of impact on schedule.

### Impact on Health Status

In thinking of the physical strains and mental strains of caregiving, the two strains tend to be "clumped" together in literature. That is, there is often a statement like "the caregiver is mentally and physically exhausted".

Archbold (1980, 1982, 1982) relates from interviewing 30 Caucasian female caregivers that "women who engage in the provider role can suffer from the unrelieved heavy physical labor of caregiving. Exhaustion and physical illness are common problems" (p. 40). In her interviews of six families, three of the families suffered at least one significant health problem since the elderly person's illness (when they started providing care). For example, a 70 year old housewife assumed full responsibility for her husband's care (he had a CVA). She suffered from sleeplessness, a weight loss of 30 pounds, and a progressive loss of vision because her glaucoma could not be treated by surgery, since she could not take time for the hospitalization required for surgery.

Archbold (1980, 1982) and Snyder and Keefe (1985) adequately discussed physical and emotional problems of the caregiver providing care for an elderly impaired relative. Archbold's study tended to mention more regarding physical problems. She states "their (caregivers) time and energy are devoted to the heavy physical labor involved in assisting the impaired person with problems of daily living" (Archbold, 1982, p. 14). Archbold (1980) from her interview of six families with caregivers stated "caregivers deprived themselves of needed medical care and rest periods because of their responsibilities to the parent" (p. 83).

Snyder and Keefe (1985) documented from a survey of primary caregivers (N = 117) that the following specific health problems were reported as a result of caregiving: (1) feeling of increased stress, tension, anxiety, burn-out, and self doubt - 47%; (20 physical and mental exhaustion, sleeplessness - 44%; (3) hypertension and other cardiac problems - 37%; (4) back problems, arthritis - 29%; (5) depression - 22%; and (6) stomach ailments, ulcers, weight changes - 22%. The longer individuals have been providing care for an elderly person, the greater the changes of suffering health problems was the conclusion of the study. Also, as mentioned earlier, elderly caregivers, because of possibility of suffering from chronic illness and from decreased strength, are at greater risk for suffering health problems as cited by Crossman, London and Barry (1981). For example, a caregiver with hypertension is at an increased risk of developing health problems from the stress of caregiving.

Likewise, Pratt et al. (1985) reported that 75% of 190 caregivers indicated that caregiving had affected their health status; 35% stated that the affects of caregiving on their health had been great. All reported, caregiving had a negative impact on their health status. The types or kinds of health problems were not specified.

Chenoweth and Spencer (1986) documented that 23% of caregivers found the emotional and physical strain of caregiving to be exhaustion and frustration. The physical and emotional strains were rated higher by the caregiver than the strain of confinement (impact on freedom) or financial strain. Here again there were no specific health problems (either mental or physical) addressed. Likewise, Robinson (1983) found that emotional strain on caregivers (N = 85) was evident, but specific symptoms were not addressed. In the next few paragraphs the impact of caregiving on the mental and physical status of the caregiver in relation to the type of caregiver (spouse, adult child, male, female) will be discussed. No studies were found on how the caregivers in various socioeconomic levels perceived the impact on their health status from caregiving. Fitting et al. (1986) compared male-spouse caregivers to female-spouse caregivers of demented partners, and found that wives reported more depressive symptoms as a result of caregiving than the husbands. (N = 25 wives; N = 24 husbands). Scales from the Minnesota Multiphasic Personality Inventory (depression, psychopathic, psychopathic deviate, paranoia, and psychasthenic) were used. In the wives, the severity score of the dementia of the partner recipient of care and the depression scores increased together. This did not occur with the husband caregivers.

In another comparison of types of caregivers (spouse, adult-child) and degree of impact on health status, Johnson and Catalano (1983) found that 17% of spouse caregivers reported that their own health had declined in the eight months of caregiving. Adult-child caregivers reported no change in health status. The number of spouse caregivers, adult-child caregivers, or other relative-caregivers was not indicated, but females dominated as caregivers, comprising 2/3 of spouse-caregivers and 57% of adult-child caregivers. George and Gwyther (1986) tend to concur in that caregiving impacted the physical and mental health of the spouse-caregivers more so than the adult-child caregivers (2.64 spouse, 1.93 adult-child; sample N = 510). Well-being indicators using four dimensions were used: physical health measured by number of physician visits in past six months and self-rating of health; mental health was measured by using a checklist of psychiatric symptoms, affect on life satisfaction, and absence or use of psychotropic drugs during past six months. Social and financial dimensions were also measured, but social impact was referred to under the sub-concept of impact on schedule; financial impact will be addressed later. An added result of George and Gwyther's study was that the caregiver's sample generally did worse in the area of mental health than the random community sample of non-caregivers.

Fengler and Goodrich (1979) found wives (N=112) caring for disabled husbands rated lower in life satisfaction scores than the average score of a national survey of men and women over the age of 65. Out of a total possible score of 36, the national average was 26, while the score of wives in the Fengler and Goodrich (1979) sample was 21. If a caregiver scores well on a life-satisfaction scale, he/she might tend to be less overwhelmed with the situation, thus, leading to less mental fatigue. In the study, role overload was a particular problem for the employed wives. One wife in the sample had two emotional collapses because of working an evening shift and taking care of her husband by herself. Fengler and Goodrich (1979) tended to agree with George and Gwyther's (1986) study, but Fengler and Goodrich were comparing just female caregivers to men and women in a national survey, whereas George and Gwyther were comparing both male and female caregivers to a random sample of male and female caregivers.

Cantor (1983) in an exploratory study, discusses the fact that the emotional strain of the caregiver in dealing with the increased frailty of the elderly recipient, was the over-riding problem for the caregiver in her study. The physical and emotional strain of the spouse caregiver was rated higher (means and one-way anova) than the adult child caregiver (spouse's emotional strain 1.76; adult-child's emotional strain 1.63; spouse's physical strain 1.76; adult-child's physical strain 1.34). Other relatives rated lower than both spouse and adult-child caregivers. Also, Cantor

(1983) documented that there were differences in perceived health of caregivers between spouse, adult-child and other relative caregivers. The results were that spouse caregivers perceived their health to be fair or poor (84%), adult-children perceived their health to be good or fair (95%) and other relatives perceived their health to be good or fair (82%). Also, 65% of adult-child caregivers perceived their health to be good compared to 10.8% of spouses and 47.6% of other relatives. Johnson and Catalano (1983) agree. The emotional strain was not defined by Cantor, as to whether the caregivers suffered from sleeplessness, anxiety, worry, or guilt.

In summary, mental and physical strain are usually studied together. Some of the symptoms mentioned as an indication of mental or physical strain for the caregiver were: tension, sleeplessness, exhaustion, burn-out, back problems, hypertension, and cardiac problems. Caregivers often deprive themselves of medical care and rest in order to care for the impaired elderly person.

Spouse caregivers appear to be at a higher risk for mental and physical problems than the adult-child caregiver. It may be due to the fact that the spouse-caregiver tends to be older and may have some chronic health problems. In one study, wife-caregivers of demented partners scored higher on a depression scale than husband-caregivers of a demented partner.

There needs to be more research on whether caregiver characteristics of sex, socioeconomic status and relationship to elderly person affects the impact on the life of a caregiver, and the impact caregiving has on their mental and physical health. Longitudinal studies are needed. Also, more comprehensive research on the actual symptoms of mental and physical strain of the caregiver is needed. There needs to be additional research on whether the caregiver perceives an influence or affect on his/her mental and physical health status or whether there is an actual affect on his/her mental and physical health status. In this study, the perceptions of the caregiver will be addressed.

### Impact on Financial Status

In this section, the only characteristic of a caregiver in which studies were found on perceived impact on financial status was the relationship of the caregiver to the elderly person. No studies documented the perception of financial burden according to socioeconomic status or sex of caregiver.

Archbold (1980, 1982), Cantor (1983), Chenoweth and Spencer (1986), Fengler and Goodrich (1979), and George and Gwyther (1986), have depicted the financial strain of providing care for an elderly impaired person in their research. The Cantor (1983) data was drawn from a large study in which 111 caregivers were interviewed. There were various types of caregivers according to relationship to the impaired elderly person: spouse, adult-child, relative, and friend/neighbor. Spouses reported the greatest degree of financial strain (1.41 in a scale of 0-2-no impact to great impact), although emotional and physical strains were higher with a score of 1.76 (scale 0-2). The adult-child caregivers reported less financial strain (.85), though it was ranked third in relation to emotional and physical strain. The relative-caregiver (sibling, niece, etc.) reported less financial strain (1.24). As with the other two groups of caregivers, emotional and physical strain was ranked higher than financial strain. Friend/neighbor caregiver strain financially was negligible (.24-scale 0-2).

Financial strain was not as persuasive an issue as anticipated though this might be due to other factors such as socioeconomic conditions and the amount of other supports within the families. Also, in Cantor's (1983) study, there appeared to be minimal impact on the caregiver's ability to keep a job or function on the job (spouse .64, adult-child .70, relative .38, and friend/neighbor 0.4 on a scale of 0-2 no impact to great impact). The need for working was probably necessary not only for financial reasons, but for emotional reasons. A job helped assure the caregiver's emotional well-being. Also, some of the impaired elderly lived alone, so the caregiver would still be able to retain a job. So from Cantor's (1983) study, the caregiver may be concerned about finances, but emotional and physical concerns were more of a problem for the caregiver.

Archbold (1980, 1982) in her exploratory study of six families with an elderly impaired person and another exploratory study of 30 Caucasian female caregivers to elderly parents, dealt with the impact of finances on the caregiver. "Funding became an issue for all families" (Archbold, 1980, p. 80). She cited families in which spouses of the caregivers had to take on an additional job in order to meet the added expenses of caring for a parent in the household. Also, a daughter resigned a job in order to assume the role of caring for her mother. The purchase of supplies and the expense of treatment over an extended period of time can be a financial strain. Although the heavy physical labor, change in life styles, and the strict rigidity of being on a schedule were more emphasized, an impact on financial status was addressed in both studies. Archbold's (1980) study was so small that the results could not be used as an indicator for the general population. Archbold (1982) also learned through comparing care managers with care providers that care managers identified career interruption and financial burden as a cost of parent-caring. The managers, as a sample, were younger and had more commitments with careers and social activities than the care providers.

Cantor's study (1983) involved a much larger sample (111) than Archbold's. Archbold (1980, 1982) disagreed with Cantor (1983) in that Cantor found that there was little impact on the ability of the caregiver to keep a job. Archbold (1980, 1982) found that a caregiver has to resign from a position, but Archbold's sample was much smaller than Cantor's, so it might not have been as representative of the general population as Cantor's.

Chenowith and Spencer's (1986) results tend to concur with Cantor (1983) in that concern for finances was listed third to emotional and physical health of the caregiver in a list of problems in providing care. In contrast, George and Gwyther (1986) found that caregivers do not experience a decrease in financial security as compared with a random sample of non-caregivers. In George and Gwyther's, study the difference in perceived impact of economic status in regard to spouse-caregiver and adult-child caregivers was insignificant, although spouse-caregivers reported significantly lower income than adult-child caregivers.

Fengler and Goodrich (1979), in an earlier study, reported that of the six wife-caregivers who scored low on a life satisfaction scale, five also felt their incomes were inadequate or barely adequate. Three of the women were employed full-time to help with costs of caregiving. None of the women who scored high on the life satisfaction scale were employed and they also felt their income was adequate for caregiving. The authors deducted that the morale of wives of the disabled men was higher when they perceived their income as adequate and when they were not employed full-time (Fengler and Goodrich, 1979).

Finally, Barnes et al. (1981) analyzed the spouse caregivers of Alzheimer's patients in a support group. The caregivers found the cost of home care services or respite care to be prohibitive for retired couples living on a fixed income. Because the illness can be prolonged for an unpredictable length of time, families are afraid to use their scarce financial resources for fear of eventual costs of nursing home care.

In summary, according to research, there is some impact on the caregivers financial status. There are mixed results as to whether impact on caregiver's financial status is significant or not and whether the caregivers perceive the impact to be significant. Archbold (1980, 1982) and Fengler and Goodrich (1979) identified that caregivers perceive financial impact to be significant but their studies involved very small samples. There needs to be additional research on whether the caregiver perceives an influence or affect on his/her financial status or whether there is an actual affect on his/her financial status. There needs to be more data on actual costs of caregiving in relation to families' incomes. This study will include perception of financial impact as affected by age, sex, socioeconomic status, and the relationship of the caregiver.

### Impact from Family Abandonment

Caregiving can have an impact on the relationship between the caregiver and other family members. In the following pages, a few studies will be mentioned regarding family relationship. There generally is not a lot of detail or literature on family relationship measures. Also, how perceived impact on family relationship is affected by caregiver characteristics is not addressed. The caregiver may either feel that it is difficult to get family support or may feel the family has given a great deal of support.

A questionnaire with open-ended items was sent to caregivers of Alzheimer's patients by Chenoweth and Spencer (1986). The question was "What are the major problems you and your family face in caring for relatives?" (p. 270). Out of 79, only four reported a lack of support from family. The population studied was more educated and affluent, so this could have some influence on types of answers. Poulshock and Deimling's (1984) did a study of 614 caregivers on the impact the elderly person's impairment (mental or physical) had on the impact of caregiving. There was a strong correlation between the disruptive behavior exhibited by the elderly person and the negative impact on elder-caregiver/caregiver-family relationships (e.g. elder had negatively affected relationship with family members and caregivers visit family friends less, r = .63).

Sibling conflicts also arise because there are "perceived inequities in contributions to care" (Archbold, 1982, p. 13) to the functionally impaired parent. The perceived inequities cause old conflicts between siblings to arise and make it difficult to have cooperation among the siblings.

Cantor's (1983) comprehensive study of factors associated with the strains of 111 caregivers (spouse, adult-child, relative, friend/neighbor) showed the following: (1) the spouse caregiver had significant impact on time spent with children and other family members (1.26 on a scale of 0-2-no impact to great deal of impact on relationships with those close to caregiver); (2) the impact on adult-child caregivers was .82 (scale 0-2) for time spent with children and other family members; and (3) for adult-child caregiver relationship with those close to the caregiver, e.g. spouse and children, the impact was .69 (scale 0-2). The specifics about the affects on family relationships was not given, but Cantor (1983) indicated that the area of impact was minimal according to the statistics, as compared with other areas such as the statistical analysis of the impact on being able to take a vacation.

Johnson and Catalano (1983) studied family supports of 115 individuals 65 years and older who were discharged from a hospital. "Conflict among family members was higher in the more dependent (24%) group of elderly care-recipients, than those considered to have more independent status (14%). This appears to be in terms of conflict between the elderly person and caregiver, rather than conflict involving other family relationships.

In thinking of relations with other family members, Scott et al. (1986) found that the majority (66 %) of caregivers of Alzheimer's patients (N = 23) reported predominately positive feelings, evidence of support from family and little if any family problems related to the care of an impaired person. None of the caregivers fell into the category of receiving little social-emotional support from family. A third perceived that they received more than enough support (33.3%); 47.6% perceived they received enough support; and 19% perceived they did not receive any family support. "Greater burden was reported by caregivers who were rated as not receiving enough support (n = 38) in comparison to the other two groups" (Scott et al, 1986, p.352). The most common family problems that were reported were lack of visits by other family members, disagreement over level of patient's mental and physical function among family members, and disagreement over type of care required for the impaired person. Apparently even with the above mentioned problems, the caregivers did not perceive a negative impact on family relationships.

Hartford and Parsons (1982), in a slightly different perspective than Scott et al. (1986), analyzed small groups (N = 8-10) of caregivers. Two themes, among other themes, were related by the caregivers. One was that some group members felt bombarded by "helpful" suggestions from other relatives, and other felt resentful that relatives didn't help more. There was also the theme of interpersonal conflict which resulted from "mutual misperception and response between two generations" (Hartford & Parsons, 1982, p. 396) if there is an adult-child caregiver. Some behavior patterns involving the relationship between the elderly person and adult-child caregiver were lifelong patterns.

A few families said the responsibility of caring for an Alzheimer's relative had drawn the family closer together. The families shared the responsibility of caring for the impaired person, such as relieving the caregiver of day-to-day care. Chenoweth and Spencer (1986) did not give percentages of families that responded positively. They also mentioned that in some families the primary caregiver was resented by others in the family who denied the problems of the elderly person. Tension in family relationships can cause destruction and disintegration of family ties. Archbold (1980) also implied that caregivers denied so much that there was strain among members of the family, that the problems were not discussed.

In summary, in some studies the impact on family relationships is addressed, but it does not appear to be the most significant area influenced by caring for an elderly impaired person. Once again, the perceived impact from family abandonment as affected by selected characteristics of the caregiver will be addressed in this study, rather than the actual disruption of family relationships. More consistent and comprehensive studies need to be done on impact of caregiving on the family.

## Summary

In summary, the following is shown by research:

1. The caregiver is usually female who is available for the elderly impaired person in serial order: the spouse first, then the adult female child, followed by other relatives. If the caregiver is an adult-child, she is usually between the ages of 40-59 years and is usually female. One person in a family is responsible for caregiving, not the family as a unit.

2. The elderly person can be functionally and/or mentally impaired to the degree that he/she needs personal and physical care and social services. The disabled elderly person's key problems may be symptom control, carrying out

of prescribed regimens, social isolation, and finding enough money to survive. Family members are needed as a supportive network for the impaired elderly person. The age of an impaired elderly person needing care can be from 65-99 years of age. The elderly person who lives alone may have less social contact with family members if health status has improved from a previous more dependent condition.

3. The burdens of caregiving can be an (a) impact on schedule (the caregiver has to follow a rigid schedule, cannot participate in social activities, may not be able to leave the elderly person alone, cannot plan a vacation, cannot do spur-of-the-moment activities); (b) an impact on one's financial status (need extra supplies, extra house, may have to resign job, though not always, may have to take on additional job); (c) an impact on mental and physical health status (sleeplessness, anxiety, back strain, hypertension, change in health status since beginning caregiving activity); and (d) an impact from family abandonment (there may or may not be family assistance and support). There may be resentment of other family members.

In this study, the perception of impact on caregivers' lives from providing care to impaired eldery persons will be addressed. This has not been done adequately in other studies. Archbold (19820 dealt slightly with perception. Also, there will be a focus on the four areas of impact which is more comprehensive than previous studies. This study involves a sample of 307, from various areas in the State of Michigan, which is a fairly large sample size.

Also, the families interviewed will all have an impaired elderly person living in the home. Many of the studies presented involved caregivers with the elderly impaired individual either living in the caregiver's home or in the community.

It has been shown in the studies presented in this chapter, that an impaired elderly person cannot live independently without assistance from someone. Usually one family member, that is a spouse or an adult child is responsible for helping and giving support to the impaired person. When one assumes the role of caregiving, there is generally impact on some dimension of a caregiver's life. In this study, the perception of impact on the caregiver will be analyzed as to whether the feelings of impact are influenced by certain caregivers characteristics such as sex, education, income and the relationship of the caregiver to the impaired person. This leads to the problem: "For elderly persons with similar functional status, how are selected caregiver characteristics related to perception of burden?".

A liturature review has been presented on the concepts of caregiver, elderly impaired person, and perceived burdens of caregiving. In Chapter IV, the methodology and procedure of data analysis will be presented.

# Chapter IV

# METHODOLOGY AND PROCEDURE

## Overview

The study design used to examine caregivers' perceptions of impact on their lives, while they are caring for an impaired elderly relative, is the focus of this chapter. Included in Chapter IV will be: 1) a description of the research design; 2) a list of operational definitions; 3) an explanation of the instruments used; 4) the selection of subjects; and 5) the procedures for data collection and analysis.

## Research Design and Hypothesis

### Design

This research is a descriptive study based on data from a cross-sectional survey. Questionnaires were used to collect information on the various dimensions of impact on the caregiver's life and on the functional status of the elderly person. Sociodemographic information was also collected. Characteristics such as sex, relationship of caregiver to the elderly person, education, and income, will be studied for their affect on the caregiver's perception of impact or burden. Also, the demographic information helps characterize the population being studied.

### Research Question and Hypotheses

The research question is: How are selected caregiver characteristics related to perception of burden?".

The hypotheses refer to several dimensions of impact: 1) impact on caregiver's schedule; 2) impact on caregiver's financial status; 3) impact on caregiver's health status; and 4) caregiver's perception of family abandonment. These four areas of impact are the dependent variables in the study. The dimensions of impact will be studied in relationship to the caregiver's sex, income and education, as well as family relationship to the elderly person. The latter variables are the independent variables in this study.

The hypotheses concerning the affects of caregiver's sex on the perception of various burdens are as follows:

1) For patients with similar functional status:
    a) The female caregiver perceives more impact on her schedule than the male caregiver.
    b) The female caregiver perceives more impact on health status than the male caregiver.
    c) The female caregiver perceives more impact on financial status than the male caregiver.
    d) The female caregiver perceives more family abandonment than the male caregiver.

The hypotheses concerning the affects of caregiver's income level on the perception of various burdens are as follows:

2) For patients with similar functional status:
    a) Caregivers in the higher socioeconomic (income and education) groups perceive less

impact on schedule than those in the lower socioeconomic group.

b) Caregivers in the higher socioeconomic groups perceive less impact on finances than those in the lower socioeconomic group.

c) Caregivers in the higher socioeconomic groups perceive less impact on health status than those in the lower socioeconomic groups.

d) Caregivers in the higher socioeconomic groups perceive less family abandonment than those in the lower socioeconomic groups.

The hypotheses concerning the affects of the caregiver's relationship to the elderly individual in the perception of various burdens are as follows:

3) For patients with similar functional status:

a) Adult-child caregivers and other non-spouse caregivers perceive greater impact on schedule than the spouse caregivers.

b) The spouse-caregivers perceive greater impact on financial status than the adult child or other relative.

c) The spouse-caregivers perceive greater impact on health status than the adult child or other relative.

d) The spouse-caregivers perceive more family abandonment than the adult-child or other relative caregivers.

## Operational Definitions

The variables that have been mentioned in the hypotheses will be operationalized in this section. Also, some criteria for inclusion in the study will be indicated:

1) The elderly individual must be 64 years of age or over and must be impaired in two or more Activities of Daily Living and/or Instrumental Activities of Daily Living.

2) The caregiver in this study is identified as a spouse, adult daughter (or in-law), or son (or in-law), or other relative (sibling, niece, nephew, etc.) who self-acknowledges that he/she is the family member who is primarily responsible for caring for a debilitated elderly person. This person can not be paid for the caregiving services. The index for caregiver is: spouse = 1; adult- child = 2; child-in-law = 3; siblings (in-law) = 4; and other relatives = 5.

3) The independent variables of sex of caregiver, income, education, and relationship of caregiver will be operationalized as follows:

   a) Sex: As indicated by respondent.

   b) Income: Total income of household such as income of spouse and care-recipient. (if spouse-caregiver) or income of adult child and/or her family (if adult-child caregiver). Income can be identified within $1,000 increments up to $10,000, then with every $4,999 (e.g. those within $10,000-$14,999) increments up to

$30,000. For the purpose of this study, income will be a continuous variable. All above $30,000 will be in same level in study. The index for income is from 1-14 (e.g. $.00 - $1,999=1, $2,000 - $2,999=2, $3,000 - $3,999=3, etc.).

c) The education levels will be divided into grade school or less, high school, college, some high school, some college or technical training, and graduate or professional degrees. (Grade school or less = 1; some high school = 2; completed high school = 3; some college or technical training = 4; completion of college = 5; graduate or professional school = 6.)

d) Relationships to the elderly person are identified as spouse, child, child-in-law, siblings (in-law), or other relative. The index for relationship to the elderly person was given under the section in which the caregiver was identified.

4) The dimensions or areas of impact of caregiving will be operationalized through a questionnaire. Questions (77 items) pertaining to the various dimensions (both positive and negative formats are mixed throughout the questionnaire or instrument (e.g. questions on finances are mixed with questions on scheduling, health and feelings of family abandonment). The questions are later factor analyzed to construct subscales for each dimension. There were

five items in the schedule dimension, 6 items in the health dimension, 4 items in the financial dimension, and 6 items in the abandonment dimension (Appendix G). Examples of statements (with the 5-point Likert-type responses) used for each dimension are:

a) Impact on caregiver's schedule: "I have to stop in the middle of my work activities to provide care." (Responses: strongly disagree = 1; disagree = 2; neither agree or disagree = 3; agree = 4; strongly agree = 5).

b) Impact on caregiver's health: "It takes all my physical strength to care for ______." (Same responses as A.)

c) Impact on caregiver's finances: "Caring for ______ has put a financial strain on my family." (Same responses as A.)

d) Family abandonment: "My family works together at caring for ______." (Same responses as A.)

5) The elderly person's functional status will be ascertained through the caregivers answering questions on the relative's need for help in activities of daily living and instrumental activities of daily living (Appendix F). An example of a question is:

a) "Does your relative need help with eating, dressing and undressing, combing hair or shaving, bathing, toileting, and getting in and out of bed?" Yes or No response (yes = 1, no = 2). An index will be calculated by totaling the number of dependencies of the elderly person that were reported by the caregiver.

## Instrumentation

There were three sources of information utilized in this study: 1) a caregiver inventory regarding how the caregiver feels caregiving has affected his/her life in such areas as daily routines, finances, health and family relationships (Appendix G); 2) questionnaires to obtain sociodemographic information on the caregiver and elderly person (Appendices D & E); and 3) a caregiver involvement questionnaire in which information on the functional level of the elderly person is elicited and can be measured (Appendix F). The caregiver's inventory and elderly person's functional status was completed by the caregiver.

### Caregiver Inventory

A 77-item (close-ended) questionnaire identifying the perceptions of impact while caring for an elderly person was developed by Dr. Charles W. Given (College of Human Medicine) and Dr. Barbara Given (College of Nursing) at Michigan State University in 1985 for their study (Caregiver Responses to Managing Elderly Patients at Home #NIA-IRO HAG06584-01) on caregiver responses. The National Institute of Aging awarded a three-year grant to study responses of caregivers managing elderly family members at home to the College of Human Medicine and the College of Nursing at Michigan State University. The inventory scale was developed through the instruments of Zarit, Reeves, and Bach-

Peterson (1980), Robinson (1983), George and Gwyther (1984), and Poulshock and Deimling (1984). The purpose of the instrument is to accurately measure the perceptions of impact of caregiving and to predict caregiver behaviors in various dimensions tapped by the scale.

The instrument consists of statements with a 5-point Likert-type responses that are supposed to reflect the caregiver's perception of impact on his/her life while caring for an impaired elderly person. Questions were asked in positive and negative formats. As mentioned in the section of operational definitions, the items on the various dimensions (impact on schedule, impact on finances, impact on health status, and feelings of abandonment) were mixed. By mixing questions, response set problems may be avoided, such as when similar questions are answered with a similar response.

### Reliability and Validity of Caregiver Inventory

Reliability refers to the degree of consistency or accuracy with which an instrument measures an attribute (Polit & Hungler, 1983). A measuring instrument is considered stable when repeated measurements will give the same result. The instrument was also administered to caregivers of Alzheimers patients and the results were similar.

The internal consistency part of reliability concerns the extent to which all the instrument's items are measuring the same variable. Chronbach's alpha coefficient measures the internal consistency of an instrument by indicating how the items are interrelated for each subscale. A higher value reflects a higher degree of internal consistency and means that there is a similar response pattern to similar questions. The values can be from 0.0 to +1.00 with higher values (.7,.8, or .9) meaning more reliability. The alpha coefficients for the subscales in the caregiver inventory ranged between .72 and .88. All dimensions were considered to be internally consistent.

Validity

Validity is the degree to which a test measures what it is supposed to measure. "Is this test valid for the purpose to which I wish to put it?" (Borg & Gall, 1983, p. 275). Do the items in the questionnaire measure accurately the perceptions of burden of caregivers of impaired elderly family members? Through a pilot study, and the administration of the questionnaire to both caregivers of Alzheimers' family members and caregivers of those elderly physically impaired, the instrument was shown to be valid in measuring the perceptions of the caregivers for this study. Also, as indicated in the literature review (Chap. III), similar type questionnaires have been used by other researchers (Zarit, et al.,1980; Robinson, 1983; Gonyea & Hooyman, 1985; Worcester & Quayhagen, 1983). These scales, used by the authors mentioned, were global in nature, whereas there is a focus on the various dimensions of caregiving in the Caregiver Inventory (Given & Given, 1985). Therefore, content validity can be supported through the literature review. Criterion validity is in the process of being established. The instrument is being utilized on various groups of caregivers of the impaired elderly. In criterion validity, a related criterion is used with which the results of the instrument can be compared (Shelley, 1984). The score of the instrument is correlated with the score of another variable (result gives an indication if instrument is valid). Is it a useful predictor? A high correlation means the instrument is a good predictor of certain variables.

### Caregiver Involvement Questionnaires

One questionnaire was utilized to measure the functional status of the elderly recipient of care so that there could be a control for the various levels of functional status. The instrument was developed by Dr. C. Given and Dr. B. Given (1985) for their study of caregiver responses.

The types of items and the functional status index were presented in the section on operationalizing the functional status of the elderly person.

## Sample & Data Collection

### Participants

The target population for this study was caregivers providing care for an impaired elderly family member 64 years or older. The elderly recipient must need assistance in two activities of daily living (e.g. toileting or dressing) and for such activities as shopping or transportation. The caregivers in the study live in the Lower Peninsula of Michigan and volunteered for the study, which means this was not a probability sample. The total sample (N=307) which was analyzed by Given and Given (1986) for their study (Grant #NIA-IRO HAG06584-01) will be utilized in this study. The University Committee on Research Involving Human Subjects approved the utilization of the sample for this project (Appendix C).

Volunteer caregivers were recruited through Visiting Nurse Associations, home-health agencies, and volunteer agencies throughout Michigan. The caregivers were contacted by agency personnel for permission to give their names to the research staff at Michigan State School of Nursing. Participants were contacted by telephone, within two weeks after they volunteered for the project, by the research staff. Screening was done at this time to insure that the families meet the criteria for the study. During the telephone interview, statements of confidentiality were assured. It was explained that answering questions was voluntary and that he/she did not have to answer all of the questions. The caregiver was surveyed regarding sociodemographic information about the caregiver, such as age, sex, and relationship to the elderly person, and about the elderly person, such as age, type of chronic illness, and activity of daily living status. The caregiver was then asked if they would be willing to participate in a longitudinal study regarding caregiving involvement and impact.

A letter was sent to the volunteer caregivers to inform them of the beginning of the next phase of the study. The participants were then called in order to evaluate if they still fit the criteria for the study. Also, appointments were arranged for interviews by the research staff in the caregivers home or caregiver's place of choice. Logs were kept of all contacts with the participants of the study.

Questionnaires (a few open-ended items, but mostly close-ended items) were sent to the participants in self-addressed envelopes prior to the time the interviewers went to the caregivers' homes. Consent forms (Appendices A & B) were also sent for the participant to sign. The form specifically covered that he/she freely consented, that the study is confidential and that the person is free to withdraw any time.

The caregivers completed the following self-administered questionnaires: 1) behaviors of the relative; 2) caregiver involvement; 3) spouse finances (household) and caregiver's finances; 4) elderly person's finances; 5) social provision scale; 6) current feelings of caregiver; 7) instrumental activities of daily living of the caregiver, such as use of telephone; and 8) caregiver's feelings about impact on his/her life. The 8th questionnaire (the caregiver inventory) will be the focus of this study, along with the Caregiver Involvement Scale (2). It is being used to measure functional status of the elderly person.

The interviewer, in a face to face interview, obtained the following information for the larger research project: 1) sociodemographic information about the caregiver; 2) sociodemographic information about the relative (the elderly recipient of care); 3) physical health of the impaired relative; 4) caregiver involvement regarding amount of medications that the elderly person takes, and management of relative's finances; 5) caregivers and elderly person's utilization of health services, such as how many times the caregiver and the elderly relative have seen a doctor in his office in past three months; 6) caregiver satisfaction about assistance from others (Appendix H); 7) physical health of the caregiver; and 8) caregiver employment. The sociodemographic information (1 & 2) and the amount of assistance from others (6) is the data which will be utilized in this smaller study.

The interviewers were trained in two-week sessions on how to conduct an interaction in order that all respondents are given the same treatment, and to help eliminate interviewer bias. The trainees practiced their skills and were observed role-playing an entire interviewing session. Also, the interviewer's role-playing was video taped, so that he/she may observe himself/herself and be aware of his/her interaction with others. The interviewer's skills were further observed through audio tapes done during actual caregivers' interviews. Also, telephone calls were made to the participants by members of the research staff, in order to assess the interaction between the caregiver and the interviewers.

## Analysis of Data

In the statistical analysis, descriptive statistics were be used to summarize the sociodemographic data. The sociodemographic information included ages and sex of the caregivers, ages and sex of the elderly persons, relationships of caregivers to the elderly persons, incomes of caregivers, and education levels of caregivers.

The inferential statistics that were performed were the one-way analysis of variance, and the two-way analysis of variance for the nominal variables in relationship to the dependent variables. Multiple regression calculations were performed in later analyses including the functional status of the elderly person. This was done for each dependent variable or each dimension (subscale) of the inventory instrument. (The data from the caregiver inventory was considered interval level data for this analysis.) Since sex of the caregiver and caregiver's relationship to the elderly person are nominal level variables, in multiple regression analysis they were converted into dummy variables. The variables represented a set of dichotomous responses. Each response, such as female, male, spouse, or non-spouse had a response of yes or no (male = 1, female = 0). With the dichotomous responses, the variables may be used in the correlation matrix and multiple regression calculation. Multiple regression was performed to determine relationships between the independent variables and the dependent variables (impact of caregiving). For the functional status of the elderly person, an index was calculated. The index was listed in the section on operationalizing the definitions. This index was entered into the multiple regression calculation.

## Methodological Assumptions

The assumptions of using the survey-type research are:

1) The respondents are able to understand the question.

2) The respondents answer the questions truthfully.

3) The questions are appropriate for this study.

## Summary

In Chapter IV, a discussion of methodology was presented. The major section of the chapter were:

1) The research is a descriptive study using a survey-type design.

2) The research question is: "How are selected caregiver characteristics related to perception of burden?"

3) The operational definitions of caregiver, elderly person, characteristics of caregiver were given. The dimensions of impact on schedule, impact on finances, impact on health status, and feelings of family abandonment were identified.

4) The instruments used were the caregiver inventory, sociodemographic information, and a questionnaire on the functional status of the elderly person.

5) Reliability was shown for the caregiver inventory.

6) The analysis of variance and multiple regression were employed for the data analysis.

In Chapter V, the presentation and interpretation of the data will be given.

# Chapter V

# Data Presentation and Analysis

## OVERVIEW

Chapter V will be divided into two sections - results and interpretation. In the first section, the descriptive statistics will be presented in order to characterize the sample and the inferential statistics (e.g. analysis of variance and multiple regression) will be presented in order to test the hypotheses. A discussion and/or interpretation of the results will be given in the second section.

In this study, the caregiver's perceptions of the impact of caregiving on his/her life (schedule, health, finance, and abandonment by family) were analyzed in relation to such variables as the caregiver's sex, income, education, and relationship to the care recipient. In addition, such variables as the ages of the caregiver and recipient of care, and the amount of assistance the caregiver received were analyzed for their relationship to certain dimensions of caregiving. Also, functional status of the elderly person was added as another independent variable in later analyses. A non-probability sample ($\underline{N}$=307) was employed from the sample of Given and Given (1985) for their Caregiver Study (Grant #NIA-IRO HAG606584-01).

The participants were considered to be appropriate after the following process:

a) 815 caregiver-patient dyads names were supplied by 145 community agencies in lower Michigan.

b) 490 met screening criteria (e.g. the elderly person was over 64 years of age; the elderly person was considered to be dependent in two activities of daily living and/or instrumental activities of daily living; and the caregiver was a family member).

c) 307 caregivers and patients of the original 490, were entered into the study. The participation rate was 63%.

Data from this sample were analyzed in order to explore the research question "How are selected caregiver characteristics related to perception of burden?". The hypotheses for each area of impact are as follows:

Schedule

1. The female caregiver perceives more impact on her schedule than the male caregiver.

2. Adult-child and other relative caregivers (such as child-in-law, sibling-in-law, and others) perceive greater impact on schedule than the spouse caregiver.

3. The caregiver in the higher socioeconomic level (income and education) perceives less impact on schedule than those in the lower socioeconomic level.

Health

1. The female caregiver perceives more impact on health status than the male caregiver.

2. The spouse caregiver perceives greater impact on health than the adult-child or any other relative caregiver.

3. Caregivers in the higher socioeconomic (income and education) level perceive less impact on health status than those in the lower socioeconomic level.

## Finances

1. The female caregiver perceives more impact on financial status than the male caregiver.
2. The spouse-caregiver perceives greater impact on financial status than the adult-child or other relative caregivers (child-in-law, sibling-in-law, other relative).
3. Caregivers in the higher socioeconomic level (income and education) perceive less impact on finances than those in the lower socioeconomic level.

## Abandonment

1. The female caregiver perceives more family abandonment than the male caregiver.
2. The spouse caregiver perceives more family abandonment than the adult-child or other relative caregivers.
3. Caregivers in the higher socioeconomic (income and education) level perceive less feelings of abandonment than those in the lower socioeconomic level.
4. Caregivers who have more assistance from family/friends perceive less family abandonment than those caregivers with less assistance from family and friends.

## Descriptive Findings

Data from several questionnaires were used to describe the sample. The subjects responded to questions about: (1) sociodemographic variables, including items on the total income level of the caregiver's or elderly recipient's household; (2) items related to perceived impact on schedule, health, finances, and family abandonment; and (3) items involving the care-recipient's level of functioning, such as activities of daily living (e.g. bathing, dressing, walking, toileting, eating), instrumental activities of daily living (e.g. use of telephone, assistance with transportation), and mobility (e.g. walking, getting around the house, getting in and out of bed). Findings are presented in the following subsections.

Sociodemographics of Caregivers

Of the sample of 307 caregivers, 257 were females and 50 males. The ages ranged from 25 to 86 years, with a mean age of 61.9 years. The percentage of caregivers above the age of 50 was 81.9%. The majority of the caregiver-elderly person dyads were white (n=283; 92.2%); 22 (7.5%) were black, one was Hispanic (0.3%), and one was American Indian (0.3%).

The distribution of the relationships of the caregiver to the care-recipient are as follows: (a) 159 or 51.8% were spouse caregivers; (b) 104 or 33.9% were adult-child caregivers; (c) 23 or 7.5% were child-in-law caregivers; (d) 7 or 2.3% were siblings-in-law caregivers; and (e) 14 or 4.6% were other relative caregivers.

The majority of the respondents completed 4 or more years of education. The number of individuals at each level is as follows: (a) 22 (7.2%) completed grade school or less; (b) 42 (13.7%) completed some high school; (c) 72 (23.5%) completed high school; (d) 107 (34.9%) completed some college; (e) 34 (11.1%) completed college; and (f) 30 (9.8%) completed graduate school or professional school.

Table 5.1: Sociodemographics Data of Caregivers and Elderly Recipients of Care

| | Caregivers N = 307 | | Elderly Recipient of Care N = 307 | |
|---|---|---|---|---|
| Sex | Male | 50 (16.3%) | Male | 154 (50.2%) |
| | Female | 257 (83.7%) | Female | 153 (49.8%) |
| Age | Mean 61.9 years | | Mean 78 years | |
| | (Range 25-86 yrs) | | (Range 63-102 yrs) | |
| Income | Spouse Mean $18,657 (N=159) | | | |
| | (Range $4500 -$30,000+) | | | |
| | (7 missing cases) | | | |
| | Non-spouse Caregiver | | Non-spouse Care Recipient | |
| | Mean $22,866 (N = 148) | | Mean $10,152 | |
| | (Range $1000 -$30,000+) | | (Range $1000 - $30,000+) | |
| | (9 missing cases) | | (14 missing cases) | |
| Education | Grade school or less | 22 (7.2%) | Grade school or less | 99 (32.2%) |
| | Some high school | 42 (13.7%) | Some high school | 50 (16.3%) |
| | Completed high school | 72 (23.5%) | Completed high school | 51 (16.6%) |
| | Completed some college | 107 (34.9%) | Completed some college | 61 (19.9%) |
| | Completed college | 34 (11.1%) | Completed college | 28 ( 9.1%) |
| | Graduate school | 30 ( 9.8%) | Graduate school | 15 ( 4.9%) |
| | | | Missing cases | 3 ( 1.0%) |

(Table 5.1 continued)

| | Caregivers N = 307 | | Elderly Recipient of Care N = 307 | |
|---|---|---|---|---|
| Relationship | Spouse | 159 (51.8%) | | |
| | Adult child | 104 (23.9%) | | |
| | Child-in-law | 23 ( 7.5%) | | |
| | Siblings-in-law | 7 ( 2.3%) | | |
| | Other relative | 14 ( 4.6%) | | |
| Employment | Spouse | 13 ( 8.2%)(N=158) | | |
| | Non-spouse | 59 (39.6%)(N=149) | | |
| Race | Caucasian | 283 (92.2%) | Caucasian | 283 (92.2%) |
| | Black | 22 ( 7.2%) | Black | 23 ( 7.5%) |
| | Hispanic | 1 ( 0.3%) | Hispanic | 1 ( 0.3%) |
| | American Indian | 1 ( 0.3%) | American | 0 ( .0%) |

Income was elicited according to the relationship of the caregiver to the recipient of care. That is, spouse caregivers reported on the total yearly household income of both spouse and care recipient. Non-spouse caregivers reported on their yearly household income, plus the total yearly income of the care-recipient. In the analyses (which are presented later) on income, spouse caregivers and non-spouse caregivers are analyzed separately. The range of household income for spouse caregivers and recipients of care (_n_=159) was from $4,500 per year to $40,000 (actually an assumed mean for the open-ended category of $30,000 and over) per year, with seven failing to respond. The mean income for spouse caregivers was $18,657, and 76.7% reported an income of $12,500 per year or more.

Among non-spouse caregivers, the yearly household income of over $30,000 was reported most frequently (48 out of 148 responses). Nine individuals did not respond. The percentage reporting over $12,500 per year was 70.9%. The mean income was $22,866. The care-recipient's income will be reported under the sociodemographic section for the elderly impaired person.

Of the 307 caregivers, 72 (23.4%) were employed, 13 of which were spouse caregivers, and 59 were adult-child or other relative caregivers. (The sociodemographic information is presented in Table 5.1.)

## Sociodemographics of the Elderly Impaired Person

The sex of the care-recipient (elderly impaired person) was evenly distributed in the sample. There were 154 males, and 153 females. The oldest care-recipient was 102 years, the youngest being 63 years of age. The mean age was 78.1 years. Race and ethnic affiliation matched that of the caregivers.

In regards to the educational level, 32.2% (n=99) completed some grade school or less, the most frequently reported level. In addition, 50 (16.3%) completed some high school, 51 (16.6%) completed high school, 61 (19.9%) completed some college, 28 (9.1%) completed college, and 15 (4.9%) had a graduate or professional school degree. There were three missing responses.

The range of patient income (for the non-spouse recipients of care) was from $1,000 per year to over $30,000 per year, with 14 individuals not responding out of 148. (The sample size was 148 because the care-recipients' income was only reported for non-spouse caregivers.) The mean income was $10,152. (The sociodemographic information is presented in Table 5.1)

In the next section, the functional status of the elderly recipient will be described.

## Description of Functional Level of Elderly Recipient of Care

In the analyses for this study, the functional status of the elderly care recipient will be added as an independent variable because it is expected that functional status of patients will also strongly affect caregivers' perception of impact. Originally it was expected that the functional status would act like a control variable in that it might mediate the relationships between the impact variables and the other independent variables. Later in the analysis it will be shown that the lack of correlation with the other independent variables preclude the use of functional status as a control variable.

In order to describe the functional level of the elderly person, respondents (caregivers) were asked to identify whether the elderly person needed assistance with: (1) activities of daily living or ADL's (eating, dressing, combing hair or showering, bathing, toileting, getting in and out of bed); (2) instrumental activities of daily living, or IADL's (shopping, getting around the house, laundry, cooking, handling money, arranging transportation); and (3) patient's mobility (walking, housework, and getting in and out of bed). One of the criteria for inclusion as a study participant was that the recipient of care was dependent in at least two ADL's and/or IADL's.

In the elderly recipients's dependencies for ADL's, the highest percentage ($n$=69, 22.5%) needed assistance with six of the activities. There were no missing responses. The percentage needing assistance with five ADL's was 17.6% ($n$ = 54). In Table 5.2, the frequencies and percentages of dependencies among ADL's for the elderly recipient are shown.

The instrumental activities of daily living are presented in Table 5.3. The highest percentage (n = 196, 63.8%) needed assistance in six instrumental activities; while 3.6% (n = 11) did not need assistance in any instrumental activities.

Table 5.2: Frequency and Percentage of Dependencies in ADL's for the Elderly Care Recipients (N=307)

| Number of Dependencies in Activities of Daily Living | Frequency | Percentage |
|---|---|---|
| No dependency | 31 | 10.1 |
| One dependency | 43 | 14.0 |
| Two dependencies | 31 | 10.1 |
| Three dependencies | 30 | 9.8 |
| Four dependencies | 49 | 16.0 |
| Five dependencies | 54 | 17.6 |
| Six dependencies | 69 | 22.5 |

NOTE: Activities of daily living - eating, dressing, combing hair or shaving, bathing, toileting, bed.

Table 5.3: Frequency and Percentage of Dependencies in IADL's For Elderly Care Recipients(N=307)

| Number of Dependencies in Instrumental Activities of Daily Living | Frequency | Percentage |
|---|---|---|
| No dependencies | 11 | 3.6 |
| 1 dependencies | 8 | 2.6 |
| 2 dependencies | 8 | 2.6 |
| 3 dependencies | 9 | 2.9 |
| 4 dependencies | 25 | 8.1 |
| 5 dependencies | 50 | 16.3 |
| 6 dependencies | 196 | 63.8 |

NOTE: Instrumental activities of daily living - shopping, housework, laundry, cooking, money, transportation.

In the elderly person's dependency for mobility, the highest percentage (n=96, 31.3%) did not need assistance according to the respondents. Seventy-five or 24.4% were dependent in 3 levels of mobility. The frequencies and percentages are presented in Table 5.4

Table 5.4: Frequency and Percentage of Dependency in 3 Measurements of Elderly Recipient's Mobility (N=307)

| Number of Dependencies in Mobility | Frequency | Percentage |
|---|---|---|
| No dependency | 96 | 31.3 |
| 1 dependency | 72 | 23.5 |
| 2 dependencies | 64 | 20.8 |
| 3 dependencies | 75 | 24.4 |

NOTE: Measurements of mobility - walking, getting around house, getting in and out of bed.

### Perceived impact

In order to describe the perceived impact of caring for an impaired elderly person on caregivers' lives, subscales from a 77-item questionnaire (caregiver inventory) on the impact of caregiving were constructed for each dimension. Originally, 111 items were developed by Given and Given (1984) and their research staff. The staff hypothesized which items measured various dimensions. After the items were tested on 99 families caring for an elderly family member in their home, the results were submitted for factor analysis. The number of items were reduced to 77 statements which measured nine dimensions (subscales) of caregiving. Four of the dimensions (schedule, health, finance, and abandonment) were used in this study.

The areas of impact were operationalized through the Caregivers' Inventory. Caregivers answered items which had Likert-type responses (1 - strongly disagree; 2 - disagree; 3 - neither agree or disagree; 4 - agree; and 5 - strongly agree). The alpha coefficients for the subscales ranged from .72 to .88. The means presented in Table 5.5 are as follows: (a) schedule 3.8 (one missing case); (b) health 2.7 (one missing case); (c) finance 2.6 (no missing cases); and (d) abandonment 2.6 (two missing cases).

Table 5.5: Means and Standard Deviations Measuring Caregivers Perception of Impact on each Dimension

| Dimension | Mean | Standard Deviation |
|---|---|---|
| Schedule | 3.8 | .804 |
| Health | 2.7 | .872 |
| Finance | 2.6 | .858 |
| Abandonment | 2.6 | .925 |

A description of the sample of caregivers and elderly persons was presented in the previous section. In the following section the hypothesis for each independent variable with each dimension of impact (schedule, health, finance, and abandonment) will be presented. The data analysis will be performed in various steps depending on the dimension of impact and the variables used. In general, an analysis of variance and multiple regression will be employed to test the hypotheses. The analysis of variance (ANOVA) is appropriate because two of the independent variables are nominal and the dependent variables are interval level data. ANOVA is employed when one desires to test the differences between two or more group means at a time such as the nominal variables of sex and family relationship in this study.

Multiple regression is appropriate since the socioeconomic data of the caregiver are measured on an interval scale. Also, in the multiple regression technique, all the data can be utilized (more than one independent variable can be entered into an equation) to help summarize and quantify relationships among the variables (the nominal variable can be changed to a dummy variable). Multiple regression offers a more complete explanation of the dependent variable. The minimal acceptable level of significance for testing the hypotheses in this study was set at .05.

The main research question is "How are selected caregiver characteristics related to perception of burden?". The first set of hypotheses to be examined are related to caregiver's sex and the affect of sex on perception of impact in each dimension.

### Analysis of Caregiver Sex for each Dimension

*Hypothesis I*: The female caregiver perceives more impact on schedule than the male caregiver.

*Hypothesis II*: The female caregiver perceives more impact on health than the male caregiver.

*Hypothesis III*: The female caregiver perceives more impact on financial status than the male caregiver.

*Hypothesis IV*: The female caregiver perceives more family abandonment than the male caregiver.

One-way analyses of variance (ANOVA) were performed to compare male and female caregivers' perception of impact for each of the dimensions (Hypotheses I, II, III, IV). Hypotheses I, II, and III were rejected. Female means were higher for each dimension, but there was not a significant difference between the perceived impact on schedule means (*p* = .165), perceived impact on health means (p*.* = .111) or perceived impact on finances (*p* = .612) for the male and female. Hypothesis IV was accepted in that there was a significant difference in group means between male and female caregivers in perception of family abandonment (*p* = .007). In the next subsection, the significance of the results will be different for Hypotheses II and IV, when there is a

Table 5.6: One-way ANOVA comparing Male and Female Caregivers Perceived Impacts from Caregiving

| | Schedule | Health | Finance | Abandonment |
|---|---|---|---|---|
| Male | 3.68 | 2.47 | 2.49 | 2.24 |
| Female | 3.85 | 2.69 | 2.56 | 2.63 |
| Total group | 3.82 | 2.65 | 2.55 | 2.57 |
| F | 1.938<br>P=.165 | 2.558<br>P=.111 | 0.258<br>P=.612 | 7.453**<br>P=.007 |

$^{**}P \leq .01$

N = 307

Scale: 1-5, strongly disagree to strongly agree

NOTE: 4 cases missing in each dimension

control for the spouse/non-spouse category in the two-way ANOVA. Four cases were missing in each analysis. (See Table 5.6 for results.) In the following subsection, the hypotheses that will be examined are related to the affect that caregiver's family relationship (to the elderly person) has on the perceived impact of the four dimensions of caregiving.

Analysis of family relationship

Hypothesis V: The spouse caregiver perceives less impact on schedule than the adult child and other relative caregivers (child-in-law, siblings-in-law, and others).

Hypothesis VI: The spouse caregiver perceives greater impact on health status than the adult-child or other relative caregiver.

Hypothesis VII: The spouse caregiver perceives greater impact on financial status than the adult-child or other relative caregivers (child-in-law, siblings-in-law, and others).

Hypothesis VIII: The spouse caregiver perceives more family abandonment than the adult-child or other relative caregivers.

Two-way ANOVA was performed for each hypothesis listed above, with sex and family relationship as the independent variables. The adult-child and other relative caregivers were categorized as non-spouse caregivers. The ANOVA for the impact on schedule by family relationship yielded a F-statistic of 5.976 with a probability value under the null hypothesis of no group differences of .015. The highest group mean was for spouses (3.91, $\underline{n}$ = 157) with the non-spouse caregivers' mean being (3.72, $\underline{n}$ = 146) (see Table 5.7). Therefore, the Hypothesis V (schedule) was rejected as stated. There was a significant difference among group means, but the unexpected finding was that there was an indication that spouses perceive more impact on schedule than non-spouses.

Hypothesis VI (health) was accepted with a significant difference ($\underline{p}$ = .001) in group means. The

Table 5.7: Means and Two-way ANOVA for Caregiver Sex and Family Relationship Affecting Impact from Caregiving

| | Schedule | | Health | | Finance | | Abandonment | |
|---|---|---|---|---|---|---|---|---|
| | Spouse | Non-sps. | Spouse | Non-sps. | Spouse | Non-sps. | Spouse | Non-sps. |
| Caregiver Sex: | | | | | | | | |
| Male | 3.69 | 3.62 | 2.43 | 2.62 | 2.45 | 2.64 | 2.06 | 2.88 |
| Female | 3.98 | 3.73 | 2.98 | 2.44 | 2.60 | 2.52 | 2.47 | 2.76 |
| Family Relationshp. | 3.91 | 3.72 | 2.84 | 2.45 | 2.56 | 2.53 | 2.37 | 2.77 |
| Total Group | 3.82<br>(N = 303) | | 2.65<br>(N = 303) | | 2.55<br>(N = 303) | | 2.57<br>(N = 303) | |
| Caregiver Sex | F = 3.737<br>P = .054 | | F = 7.202**<br>P = .008 | | F = 3.47<br>P = .556 | | F = 3.734<br>P = .054 | |
| Family relationship | F = 5.976*<br>P = .015 | | F =20.938***<br>P = .000 | | F = .170<br>P = .680 | | F = 11.017***<br>P = .001 | |
| Two-way Interaction | F = .376<br>P = .540 | | F = 5.697*<br>P = .018 | | F = .693<br>P = .406 | | F = 2.592<br>P = .108 | |

*P $\leq$ .05
**P $\leq$ .01
***P $\leq$ .001

Note: Male Spouse N = 39
Male Non-spouse N = 11
Female Spouse N = 118
Female Non-spouse N = 135
Four cases missing each dimension

spouse mean (2.84, n = 157) was the highest in perceived impact on health with the non-spouse caregiver mean being 2.45 (n = 146). Therefore, the results indicate that spouse caregiver perceive more impact on health.

There was no significant difference (p = .680) in group means for impact on financial status among spouses (2.56, n = 157), and non-spouse (2.53, n = 146). Hypothesis VII (financial) was rejected. There was a perception of impact but there does not appear to be a significant difference in perceived impact in finances among various family members.

For the dimensions of abandonment (Hypothesis VIII), the ANOVA yielded a probability value under the null hypothesis of no-group difference of .001. The hypothesis was rejected as stated since the non-spouse mean (2.77, n = 146) was the highest, compared to the spouse mean of 2.37 (n = 157). There was a perception of impact from abandonment, but the non-spouse caregivers perceive more impact than the spouse caregivers, contrary to the hypothesis. In the analyses for each dimension, four cases were missing. Results are presented in Table 5.7.

### Other Findings (sex and family relationship)

The relationship of family relationship on each dimension of impact was presented as calculated through a two-way ANOVA. Caregiver sex was also included in the two-way ANOVA procedure in order to assess if there is an interaction between caregiver sex and family relationship of the caregiver.

As mentioned for perceived impact on schedule and perceived family abandonment, the family relationship was significant (_p_ = .015, spouse mean higher for impact on schedule, and _p_ = .001, non-spouse mean higher for abandonment). Caregiver sex and the two-way interaction of the two variables were not significant for impact on schedule or abandonment. In financial impact, sex and family relationship were not significant and the two-way interaction of the two variables was not significant.

Regarding the perceived impact on health, the variables of caregiver sex (_p_ = .008) and family relationship (_p_ = .000) were significant. There also was a significant two-way interaction between the two variables (_p_ = .018). That is, the affect caregiver sex has on the perceived impact on health depends on whether the caregiver is a spouse or non-spouse, or the affect family relationship has on the perceived impact on health depends on whether the caregiver is male or female. There were four missing cases in the analysis. (Results are presented in Table 5.7.) The last set of hypotheses to be examined are related to the socioeconomic status of the caregiver and its affect on the caregiver's perceived impact for each dimension.

Analysis of Socioeconomic Variables

Hypothesis IX: Caregivers in the higher socioeconomic level (income and education) perceive less impact on schedule than those in the lower socioeconomic level.

Hypothesis X: Caregivers in the higher socioeconomic level (income and education) perceive less impact on health status than those in the lower socioeconomic level.

Hypothesis XI: Caregivers in the higher socioeconomic level (income and education) perceive less impact on finances than those in the lower socioeconomic level.

Hypothesis XII: Caregivers in the higher socioeconomic (income and education) level perceive less family abandonment than those in the lower socioeconomic level.

To determine the affects of the socioeconomic status on the impact of caregiving, multiple regression was performed. At this time, the elderly person's functional status (PADL's, PIADL's, and PMOBL's) and caregiver sex, were added to the equation. The purpose is to determine if there are any differences in the affect of the variables on the perceived impact of caregiving even when there is a control for the functional status of the elderly recipient. One measurement, getting in and out of bed, is utilized in both PADL'S and PMOBL's.

Multiple regression analysis was performed on spouse and non-spouse caregivers separately because income was reported according to a different format in the two groups. For non-spouse caregivers, caregiver income and patient income were used instead of spouse income. The other variables utilized were spouse income, caregiver education, and caregiver sex. In the correlation matrix for schedule, there was a relationship among the variables of schedule with caregiver sex (-.148), PADL (.341), PIADL (.281), and

PMOBL (.282). There is also an intercorrelation between a spouse income, PADL (-.111), and PMOBL (-.127). The most significant variables for impact on schedule were caregiver sex, PADL, and PIADL (having most influence). The combined influence of these variables accounted for almost 20% variance of the impact on schedule. A summary of the results are in Table 5.8.

Table 5.8: Multiple regression for spouse and non-spouse caregivers' perceived impact on schedule utilizing elderly recipient's functional status, caregiver sex, and socioeconomic status

Dependent Variable: Schedule

| Independent Variables | Beta | Significance |
|---|---|---|
| Spouse | | |
| Spouse Income | .027 | .743 |
| Caregiver Education | -023 | .781 |
| Caregiver Sex | -174 | .022* |
| PADL | .227 | .033* |
| PIADL | .237 | .002** |
| PMOBL | .095 | .361 |
| | | $R^2$ .196 |
| Non-spouse | | |
| Non-spouse Caregiver Income | .048 | .600 |
| Patient Income | -.044 | .629 |
| Caregiver Education | .107 | .253 |
| Caregiver Sex | -.062 | .456 |
| PADL | .188 | .104 |
| PIADL | -.036 | .669 |
| PMOBL | .234 | .046* |
| | | $R^2$ .147 |

*$p \leq .05$
**$p \leq .01$
***$p \leq .001$

In computing multiple regression for the non-spouse caregivers, there was a correlation among the variable of caregiver educational level (-.119) PADL (.349), PMOBL (.362) and schedule. There was a negligible correlation, (that is below .1) between schedule and each of variables, caregiver income, patient income, and caregiver sex. In the final equation, PMOBL (_p_ = .046) was the only significant variable. Caregiver sex (_p_ = .456), caregiver income (_p_ =.600), patient income (_p_ = .629), caregiver education (_p_ = .253), PADL (_p_ = .104), and PIADL (_p_ = .669) were not significant (results in Table 5.8). Therefore, Hypothesis X, which stated that the caregivers in higher socioeconomic level perceived less impact on schedule than those in the lower socioeconomic level was rejected. This finding indicated that socioeconomic status does not have a relationship to the caregiver's perceived impact on schedule. The multiple regression analysis was computed for impact on health status, again analyzing spouse and non-spouse caregivers separately. Spouse income and education, caregiver sex, PADL's, PIADL's, and PMOBL's for spouse caregivers were analyzed and caregiver income and patient income was substituted for spouse income, when non-spouse caregivers were analyzed. For spouse caregivers there were correlations above the level of .100 for the variables of caregiver sex, spouse income, PADL, PIADL, and PMOBL with the dependent variable of health. There were also intercorrelations above .100 with the following: caregivers sex and caregiver income (.106); caregiver income and caregiver education (.412); caregiver income and PADL (-.111); and PMOBL and caregiver income (-.128).

The only significant relationship was caregivers sex and PIADL (Table 5.9) with the combined influence of all the variables accounting for a 17% variance in impact on health. The results indicate that these two variables, rather than socioeconomic status, may influence the caregiver's perception of impact on spouse caregiver health.

For non-spouse, there was a correlation (above .1 between health and each of the following independent variables: caregiver income, patient income, caregiver education, PADL, and PMOBL. There were intercorrelations between caregiver income and caregiver education, PADL and PMOBL, and patient income and caregiver income. The only significant variable was PADL, which with the combined influence of all the variables accounted for 14% variance in perceived impact on caregiver's health. The Hypothesis X stating that caregivers in the higher socioeconomic status perceived less impact on health than those in the lower socioeconomic status was rejected. (Results in Table 5.9.)

In analyzing financial impact for both spouse and non-spouse caregivers, the same variables were utilized as in the dimensions of schedule and health. Spouse income was the only significant variable, which with the other variable accounted for a combined influence of a 15% variance for spouse's perceived impact on finances (see Table 5.10). There were correlations (above .100) between the dependent variable finance and each of the following variables: spouse income (-.305), PADL

Table 5.9: Multiple regression for spouse and non-spouse caregivers for perceived impact on health - utilizing recipient's functional status, caregivers sex, and socioeconomic status.

Dependent Variable: Health

| Independent Variables | Beta | Significance |
|---|---|---|
| Spouse | | |
| Spouse Income | -.037 | .653 |
| Caregiver Education | -.040 | .628 |
| Caregiver Sex | -.257 | .001*** |
| PADL | .088 | .410 |
| PIADL | .198 | .012* |
| PMOBL | .168 | .112 |
| | | $R_2$ .176 |
| Non-spouse | | |
| Caregiver Income | .028 | .761 |
| Patient Income | -.081 | .382 |
| Caregiver Education | -.141 | .121 |
| Caregiver Sex | .087 | .299 |
| PADL | .214 | .069 |
| PIADL | -.103 | .235 |
| PMOBL | .097 | .410 |
| | | $R_2$ .148 |

$*p \leq .05$

$***p \leq .001$

(.247), PMOBL (.234), and caregiver education (-.111). There were intercorrelations (above .100) between spouse income and PADL, and spouse income and PMOBL.

Hypothesis XI (Financial) was accepted for spouse caregivers in regards to spouse income being significant but was rejected for non-spouse caregivers. For non-spouses, socioeconomic status does not appear to be significantly related to the perceived impact on financial status, although the coefficients were in the expected direction.

In the analysis of the dependent variable abandonment, based on socioeconomic status for both

Table 5.10: Multiple regression for spouse and non-spouse caregivers for perceived impact on finance utilizing recipient's functional status, caregiver sex, and socioeconomic status.

Dependent Variable: Finance

| Independent Variables | Beta | Significance |
|---|---|---|
| Spouse | | |
| Spouse Income | -.279 | .001*** |
| Caregiver Education | .010 | .903 |
| Caregiver Sex | -.065 | .394 |
| PADL | .132 | .224 |
| PIADL | .074 | .351 |
| PMOBL | .097 | .360 |
| | | $R^2$ .152 |
| Non-spouse | | |
| Caregiver Income | -.156 | .100 |
| Patient Income | -.086 | .358 |
| Caregiver Education | -.152 | .119 |
| Caregiver Sex | .056 | .503 |
| PADL | .125 | .286 |
| PIADL | -.106 | .224 |
| PMOBL | -.044 | .708 |
| | | $R^2$ .142 |

***$p \leq .001$

spouse and non-spouse caregivers, spouse income and caregiver sex were the only significant variables. The variance for the combined influence of all the variables was approximately 8%. There was a negligible correlation of less than .1 between abandonment and each of the functional status variables PADL, PIADL, and PMOBL. The correlation between spouse income and the dependent variable of abandonment was .145. There were intercorrelations (above .100) between spouse income and PADL and spouse income and PMOBL. For non-spouse caregivers, the only correlation above .100 with abandonment was PMOBL. Caregiver income was intercorrelated (above .100) with PADL and PMOBL, but patient income or caregiver education were not intercorrelated with the functional status of the elderly person.

Hypothesis XII (Abandonment) was rejected for spouse and non-spouse caregivers as stated. Spouse income was significant, although the effect was opposite from what was expected. Spouses with a higher income level perceive more abandonment than those with lower income. The results are presented in the following table (Table 5.11).

Table 5.11 Multiple regression for spouse and non-spouse caregivers in perceived impact from abandonment utilizing elderly recipient's functional status, caregiver sex, and socioeconomic status.

Dependent Variable: Abandonment

| Independent Variables | Beta | Significance |
|---|---|---|
| Spouse Income | .176 | .047* |
| Caregiver Education | -.004 | .962 |
| Caregiver Sex | -.203 | .012* |
| PADL | .046 | .683 |
| PIADL | .075 | .362 |
| PMOBL | .062 | .575 |
| | | $R^2$ .076 |
| Non-Spouse | | |
| Caregiver Income | .068 | .491 |
| Patient Income | -.086 | .379 |
| Caregiver Education | -.005 | .958 |
| Caregiver Sex | .038 | .665 |
| PADL | -.135 | .277 |
| PIADL | -.057 | .531 |
| PMOBL | .205 | .104 |
| | | $R^2$ .042 |

$*p \leq .05$

Hypothesis XIII Caregivers who receive more assistance from family/friends perceive less family abandonment than those caregivers who receive less assistance from family and friends.

An added hypothesis was examined in the dimension of abandonment. The independent variables of frequency of times family helps and the number of relatives who provide help, caregiver sex, family relationship, PADL, PIADL, and PMOBL, were analyzed through multiple regression for the dimension of abandonment. Frequency of help was significant, but number of persons helping, PADL, PIADL, and PMOBL were not significant. Therefore, Hypothesis XIII is accepted. A summary of the results are given in the following table (5.12).

Table 5.12: Multiple regression for impact from abandonment utilizing assistance, elderly recipient's functional status, caregiver sex, and family relationship.

Dependent Variable: Abandonment

| Independent Variables | Beta | Significance |
|---|---|---|
| Persons helping | -.114 | .058 |
| Frequency of help | -.269 | .000*** |
| Caregiver sex | -.118 | .044* |
| Family relationship | -.244 | .000*** |
| PADL | -.027 | .726 |
| PIADL | .077 | .180 |
| PMOBL | .063 | .410 |
| | | $R^2$ .163 |

*$\underline{p} \leq .05$
***$\underline{p} \leq .001$
$\underline{N} = 267$

In the following section, the interpretation of the results will be presented.

# Interpretation of Results

## Sociodemographics of the Caregiver

### Sex and Age

Of a sample of 307 caregivers, the majority were females - 257 females and 50 males. These findings are consistent with other researchers such as Archbold (1982), Snyder and Keefe (1985), George and Gwyther (1986), Hawranik (1985), Cantor (1983), and Scott, Roberto, & Hutton (1986). George and Gwyther (1986), as an example, presented the fact that 71% of caregivers in their study were women. In this study, 83.7% were females and 16.3% were males. Actually, there was a higher percentage of women than some other studies, such as Montgomery, Gonyea & Hooymen (1985) with 73.5% females and Chenowith and Spencer (1986) with 77% females.

The average age of the caregiver was 61.9 years with 81.8% being over the age of 50. In George and Gwyther's study (1986), the average age was 57, and in Cantor's (1983) study, the average age was 57.5 years. (Spouse, adult child and other relative caregivers were studied by these authors.) Day (1985) states that the majority of offspring caring for a disabled parent are over 50, and the average age of a spouse caring for a disabled person is 66. In this study, the average age of 61.9 years probably reflects the fact that there were more spouse caregivers than adult-child caregivers or other relative caregivers. Thus, the mean age is slightly higher than in other studies.

Race, Education, and Income

Caucasians dominated the sample (283, 92.2% of N = 307). Only twenty-two caregiver-patient dyads were black (7.2%) and one was Hispanic (.03%). The distribution of Caucasians, blacks, and Hispanics is not typical of the larger population of lower Michigan. Caucasians dominate the population at approximately 80%, whereas the percentage of Blacks is approximately 19% and Hispanic is approximately .07%.

The educational level of caregivers was fairly high in that 55.8% (n = 170) of the sample encompassed a group that had either completed some college (34.9%), had completed four years of college (11.1%), or had completed graduate or professional school (9.8%). According to the U.S. National Center for Health Statistic (1986) of those 55 years and over, 11.2% have completed one to three years of college, and 11.7% have completed four years of college. Of the sample, 23.5% completed high school, 20.8% completed some high school, and 7.2% attended grade school. The percentage completing high school was low according to the U.S. National Center for Health Statistics (1986), in that 34.2% of those 55 years old and over have completed high school; but those in the sample attending college or more was higher than average. These figures compare approximately the same to George and Gwyther's (1986), Zarit, Todd and Zarit's (1986), and Scott's et al. (1986) studies in which caregivers completed a level of 13 years or more of education. Cantor (1983) showed a contrast in that most of the caregivers in her study had graduated from high school or attended school to 12th grade or less (67.5%, N = 111).

In regards to income of the caregivers, total yearly household income was separately recorded for the spouse caregivers and non-spouse caregivers (adult child and other relatives). For spouse caregivers, the income levels ranged from $4500 to over $30,000 per year with $17,500 per year the most frequently reported (36 of N = 159) The mean was $18,657, slightly lower than the mean of the caregiver household income of 18,800 (before taxes) for those 65 years and older reported by the U.S. Bureau of Census (1985). There were 76.7% above $12,500/year. For non-spouse caregivers, the most frequently reported yearly income was over $30,000/year (48 of N = 148). The income ranged from $1,000 to over $30,000 for non-spouse and the mean was $22,866. This mean is lower than the household mean income of $28,149 for the Midwest reported by the U.S. Bureau of Census (1985).

In comparing results of studies, the finding is in agreement with George & Gwyther (1986), who reported that household income of spouse-caregivers' is usually lower than the household income of adult-child caregivers'. The income levels (for this study) are slightly higher than those reported by Zarit et al. (1986), Scott et al. (1986), Chenoweth and Spencer (1986), and Montgomery et al. (1985), in which the caregiver income levels were from $4,800 to $30,000 per year. The financial levels of caregivers are difficult to compare from one study to another because of: (1) the inflation rate since the time of data collection for other studies; (2) the inconsistent mixture of caregiver relationships from one study to another (some have more spouse caregivers and/or adult-child caregivers); and (3) difference in reporting of income from one study to another.

The mean income of the care-recipient of the non-spouse caregiver was $10,152.00, which is slightly lower than the mean income of $10,622, reported by the U.S. Bureau of Census (1985), per individual 65 years and over before taxes. (The care-recipient of spouse caregiver was included in spouse-caregiver's total yearly income.) It is difficult to compare with other studies, since income of the elderly impaired individual is rarely mentioned. According to Exter (1987), the median income of those 65-74 is $15,400 and among those 75 years and over, the median income is $10,500. The income level in this study, at least of the impaired elderly receiving care from non-spouse caregivers is congruent with Exter's findings.

In general, the respondents in this sample tend to be white and well educated, as has been reported in many

other studies (Fitting, Robins, Lucas, and Eastham, 1986; Worcester and Quayhagen, 1983; Zarit et al., 1986; Johnson and Catalano, 1983; George and Gwyther, 1986). The reason may be that the questionnaires are lengthy. The more educated individual may be less intimidated by the complexity of the study, and he/she may have a better understanding of the purpose for research. Also, the white population may use community services more, such as the Visiting Nurse and Home Health Agencies, where recruitment was most often initiated. McAuley and Arling (1984) state that "people with greater education and more social resources receive more services" (p.62). They also report that education (which may mean a higher socioeconomic status) is probably indicative of knowledge about services, and thus influences individuals acceptance and ability to obtain formal care.

## Relationship of Caregiver to Elderly Person

The majority of the respondents were spouse caregivers (51.8% or n = 159). Adult-child caregivers comprised 33.9% n = 104), and the other 14.4% consisted of child-in-law caregivers (n = 23 or 7.5%), other relative caregivers (n = 14 or 4.6%), and siblings-in-law caregivers (n = 7 or 2.3%). Spouses and adult children are typically the caregivers in many studies. According to George (1984) and Day (1985), the elderly receive personal care first from the spouse (if living), then from a daughter if the elderly person is a widow or

widower. In Johnson's (1983) study, the support given to post-hospitalized individual ages 65 years and older was provided by spouses. Among 167 families, 45% identified the spouses as a primary caregiver, and 39% identified the child. Johnson & Catalano (1983)(N = 167) also found that 62% were spouses and 27% were children in their study. This study is congruent with other studies, in which spouses comprise more of the caregivers than do adult children (Snyder & Keefe, 1985; Scott, Roberto, & Hutton, 1986; and George & Gwyther, 1986).

For this study, there was a self-selection process. The participants were selected because they met the criteria of being a caregiver and other criteria for the study.

### Sociodemographics of the Elderly Recipient

There was an even distribution of males and females as recipients of care in the sample (male n = 154, females n =153). This distribution of male and female is not congruent with Johnson and Catalano (1983), Cantor (1983), and Archbold (1982), who presented samples in which most recipients of care were women. It is congruent with Snyder and Keefe (1985) who found an even split of males and females (M = 61, F = 56). Generally, women live longer than men, but the distribution of female to male can depend on criteria used for study. The factors that led to an even distribution between males and females in this study are unknown.

The mean age of the elderly impaired person was 78.1 years (63 years to 102 years). One of the criteria for the study was that the elderly recipient be 65 years or older. The mean age is congruent with the studies in which the impact of caregiving on both spouse caregivers and non-spouse caregivers is examined. For example, Johnson (1983) documented a mean age of 74.5 years, Worcester and Quayhagen (1983) a mean age of 77 years, and Pratt, Schmall, Wright, & Cleland (1985) a mean age of 75.3 years. Any differences in distribution of age in a sample will be evident depending on the age limits and/or criteria for the study.

The educational level is not addressed in most studies. There seems to be a rather even distribution between those who just attended grade school and some high school and those who completed high school and higher levels of education (32.2% completed some grade school; 16.3% completed some high school; 16.6% completed high school; 19.9% completed some college; 9.1% completed college; 4.9% have a graduate school or professional degree). According to the U.S. National Center for Educational Statistics, less than half (30.8%) of the current older population completed high school, 48.8% completed less than high school, 10.5% attended 1-3 years of college, and 9.9% completed four years of college. In this sample population, the percentage of high school graduates appears low for the general population, but the percentage for post-high school education appears high.

## Functional Level of the Elderly Person

The functional status and/or dependency level of the elderly recipient of care is difficult to compare among studies. There are various measures utilized for functional status such as: (1) supervision needed; (2) management of incontinence; (3) diagnosis of the elderly person; (4) activities of daily living status; and (5) cognitive or behavioral status of the elderly person.

The Activities of Daily Living, the Instrumental Activities of Daily Living, and three measures for mobility status were utilized in this study. The highest percentage (n = 69, 22.5%) of the 307 elderly recipients needed assistance with six of the activities of daily living (eating, dressing, combing or shaving, bathing, toileting, and getting in and out of bed). The next highest was 17.6% (n = 54) needing assistance with five ADL's, and the third highest was 16.0% for assistance with four ADL's (n = 49). In all 56.1% needed assistance with four or more ADL's. In the instrumental activities of daily living 63.8% (n = 196) needed assistance with six IADL's (shopping, housework, laundry, cooking, money, and transportation).

In mobility 31.3% of patients (n = 96) do not need assistance with any of the measured dependencies (walking, getting around the house, and getting in and out of bed. Seventy-five (24.4%) of patients were dependent in three of the mobility activities, whereas 64 (20.8%0 needed assistance with two mobility measurements. A total of 67.7% who needed assistance with mobility. The studies such as George and Gwyther (1986), Sirshal (1985), Hawranik (1985), and Paulshock, Gary, and Deimling (1984) differ in measurements of impairment, and do not agree as to whether functional impairments affect the perception of impact from caregiving. The functional measures were used as independent variables for inclusion in this study in the final analyses. Recipients of care in this study had to be dependent in two areas of either activities of daily living or instrumental activities of daily living.

### Perception of Impact (Schedule, Health, Finance, and Abandonment)

The sample means for perception of impact for each dimension are as follows: (a) schedule 3.8 (S.D. .804); (b) health 2.7 (S.D. .872); (c) finance 2.6 (S.D. .858); and (d) abandonment 2.6 (S.D. .925). The sample mean for the dimension of schedule is the highest of the four dimensions, possibly suggesting that the caregiver experiences the most impact in this area.

The health mean is second highest mean, with finance and abandonment having the same and lowest means. Comparing these data with other research findings is impractical because similar measures were not used. In some research, the dimensions were studied in a global sense, such as Zarit's Burden Scale (1980), Robinson's (1983) Caregiver's Strain Index on confinement, emotional, physical and financial areas, and Montgomery's et al. (1985) inventory for objective burden. Cantor (1983) documented perception of health using emotional and physical strain with a response of no impact to great deal of impact (scale 0-2). The mean for the entire sample (N = 111) was 1.56 for emotional strain and 1.41 for physical strain. The results show that there is some impact on health as in this study, but results cannot be compared because of different measurements. In Cantor's study, the scale of no impact to a great deal of impact (0-2) was the measurement for financial impact. This author presented the fact that financial impact scored the lowest (.91) for the group, as is true in this study. The results of this study and Cantor's study could indicate that finances are of less concern than the other dimensions of impact, or respondents are reluctant to admit that caregiving to a loved-one is having an impact on their financial status.

In thinking of the caregiver's perception of family abandonment, the standard deviation (.925) for this dimension (subscale) was the largest compared to the three other dimensions. This represents a higher variability in the scores. Scott, Roberto and Hutton (1986) measured family support, but the perception of family support was not addressed, thus, the results in from this study cannot be compared to Scott's et al. (1986).

In summary, the majority of the 307 caregivers were females (83.7%). The average age of the caregivers was 61.9 years, which probably reflects that the there were more spouse caregivers (51.8%) than adult-child caregivers (33.9%). The caregivers mean age was slightly higher than other studies, such as Cantor (1983) and George and Gwyther (1986). Spouses and adult-children are typically the caregiver, as shown in other studies. According to Day (1985), the elderly receive personal care first from a spouse (if living), then from a daughter, if the elderly person is a widow or widower.

The distribution of race for the caregiver-patient dyad was Caucasians, 92.2%; blacks, 7.2%; and Hispanics 0.3%. The distribution of Caucasian, blacks, and Hispanics is not typical of lower Michigan where Caucasians dominate the population at approximately 80%. The percentage of Blacks in lower Michigan is approximately 19% and Hispanics approximately .07%. The respondents appear to be well-educated in that 55.8% encompassed a group that had either completed some college, had completed four years of college, or had completed graduate or professional school. This has been shown in other studies such as George and Gwyther, 1986, and Zarit et al., 1986. More educated individuals may be less intimidated by the complexity of the study.

There was an even distribution of male and female recipients of care (males N = 154, females N = 153). Most recipients of care tend to be female because women tend to live longer than men, so the distribution was an unexpected finding. The mean age of the elderly person was 78.1 years, which is congruent with other studies.

In regards to functional status of the elderly person, the dependency level is difficult to compare with other studies of differences in measurements employed by researchers. Of the 307 elderly recipients, 56.1% needed assistance with four or more ADL's (eating, dressing, combing or shaving, bathing, toileting, and getting in and out of bed). In the instrumental activities of daily living (shopping, housework, laundry, cooking, money and transportation), 63.0% needed assistance with six. Seventy-five elderly were dependent in three mobility activities (walking, getting around the house, and getting in and out of bed), whereas 64 needed assistance with two mobility measurements. Studies are contradictory in whether impairment of the elderly person affect perception of impact from caregiving.

In looking at the means for the perception of impact for each dimension, schedule had the highest mean (3.8), with the health mean being the second highest (2.7). Finance and abandonment were the same with a mean of 2.6. Comparing these means with other studies is impractical because similar measures were not used.

## Interpretation of Hypotheses

In the next subsection, the interpretation of the hypotheses will be discussed. Each hypothesis will be presented for each caregiver characteristic, a statement will be given as to its acceptance or rejection, then an interpretation will be given. The functional status of the elderly person was not entered into analysis initially but was added in later analyses. A summary of the hypotheses is presented in Table 5.13.

Caregiver sex

Hypothesis I: The female caregiver perceives more impact on her schedule than the male caregiver.

The hypothesis was rejected on the basis of an analysis of variance ($F = 1.938$, $p = .165$). In looking at mean differences between male and female caregivers, the female perceives more impact on schedule than the male caregiver, but the results were not statistically significant. The results are tentatively congruent with Robinson (1983), Pratt, Schmall, Scott, Wright and Cleland (1985), who used global burden scales and did not analyze the dimension of impact on schedule. Zarit, Todd, & Zarit (1986) initially reported that there was more caregiver burden (Caregiver Burden Scale) by wives than husbands, but after a two year follow-up there were no significant differences between sexes. Johnson (1983) also reported that less caregiving strain was reported by husbands than wives.

The results are mixed. There were no studies specific for impact on schedule by sex differentiation. In this study, the sample consisted mostly of women, so the comparison between sexes might not have been statistically practical. Also, the items might not have properly tapped a male's perspective of impact on schedule. There was no control for length of time of caregiving, which could have an effect on respondents' answers. For example those providing care for a long period of time may perceive less impact on schedule than those who have provided care for a shorter period of time. The longer term caregivers may have become accustomed to the schedule of caregiving.

Hypothesis II: The female caregiver perceives more impact on health status than the male caregiver.

The hypothesis was accepted as computed by a two-way analysis of variance ($F = 7.202$, $p = .008$). (In the one-way ANOVA, the hypothesis was rejected, but the results of the two-way ANOVA was preferred.) Also in later analysis, the hypothesis was confirmed by the multiple regression procedure. The direction of the mean difference was that females perceive more impact on health than male caregivers when the spouse/non-spouse category is controlled. The acceptance is in agreement with Fitting et al. (1986) who found that female spouse caregivers reported more depressive symptoms than husbands, using a one-way analysis of variance (Minnesota Multiphase Personality Inventory). As mentioned in Hypothesis I, Zarit et al. (1986) reported more caregiver strain for wives than husbands (Caregivers Burden Scale), but after two years there was no significant difference in strain between sexes. There is a possibility that the men, who are living and are caregivers, are healthy. Once again the measurements and methods were not the same. The items in this study require Likert-type responses to questions about general physical health, not specific symptoms. Regarding physical or mental symtomatology, the items may have been too general to tap the differences in health status between male and female caregivers.

Hypothesis III: The female caregiver perceives more impact on financial status than the male caregiver.

The hypothesis was rejected since the results from the ANOVA were not significant ($F$ = 0.258, $p$ = .612). (The female mean was higher than the male mean, but was not significant.) No studies were found that documented the perception of financial impact according to the caregiver's sex. Zarit et al (1986) and Fitting et al (1986) reported that wives perceive higher burden than husbands, but an unidimensional scale (financial items included) was utilized. Male and female caregivers may have similar financial concerns, such as spouse caregivers, male or female, have one household income. An adult-child may be able to utilize the elderly person's income, thus, no differences in perception of financial impact.

*Hypothesis IV*: The female caregiver perceives more family abandonment than the male caregiver.

The hypothesis was accepted (*F* = 7.453, *p* = .007). In the two-way ANOVA, there was not a significant impact for the female when there was a control for the spouse/non-spouse category. (The female spouse mean was higher than the male spouse, but not significantly.) Later in the analysis, through multiple regression, the female spouse caregiver was shown to perceive a significant impact from family abandonment. Therefore, Hypothesis IV will be accepted. The impact of family abandonment for caregivers was not documented in much detail and the impact according to caregiver characteristics was not addressed. One reason for perceived differences is that women are expected to be a "caregiver" if needed. It is not an expected role for males. Therefore, a male may receive more assistance from others, so perceive less abandonment (Johnson, 1983).

Women may feel abandoned because of society's expectation that a women traditionally assumes a caregiving role. Once she becomes a caregiver, she receives less family or friend assistance than possibly a male. For the adult-daughter, the extra responsibility of taking care of a parent, along with the responsibilities of child-rearing, taking care of a household, and possibly being employed, leads to feelings of lack of assistance in order to complete all of her tasks. Also, daughters tend to help with more 'hands on' assistance for the elderly person, such as personal care, meal planning, and treatments than male sons (Horowitz, 1985). The older woman may resent becoming a caregiver to a husband because she was looking forward to personal opportunities and growth, plus she is living alone with her husband, so feels abandoned. An older women may not be accustomed to making decisions about household problems, financial problems, so feels frustrated and alone (feels there is no one to help) when she now has all the responsibility. More multiple demands appear to be placed on women than men.

In continuing with the domain of abandonment, frequency of help, number of persons assisting the caregiver, family relationship, and caregiver sex were analyzed using multiple regression. Frequency of help (.000), family relationship (.000), and caregiver sex (.044) were statistically significant. This finding helps support the calculation through the ANOVA procedure that males perceive less abandonment than females. The functional status of the elderly recipient of care was minimally correlated (less than .1) with abandonment and was not significant. Therefore, the results indicate that frequency of help may influence the perception of abandonment, but with the variance just being approximately 16%, there are other explanations for impact from abandonment that were not analyzed in this study.

Family relationship

> Hypothesis V: The spouse caregiver perceives less impact on schedule than the adult-child caregiver and other relative caregivers (child-in-law, siblings-in-law, and others).

The hypothesis is rejected as stated. There was a significant difference in means ($F$ = 5.976, $p$ = .015), but the unexpected finding was that the spouse mean (M = 3.91) was higher than the non-spouse mean (M = 3.72). This finding is not congruent with Johnson (1983) who documented that social activities were curtailed more for adult-children and other caregivers rather than spouses. Once again, the measurements and methods were different in Johnson's study. Cantor's (1983) results contradicted Johnson's (1983) in that spouses reported more severe impact on specific areas such as time to do things like hobbies, , and time to socialize with friends, than adult-children reported. George & Gwyther (1986) reported that the means for spouse and adult-child caregivers on a satisfaction with social activity scale (an objective assessment) were the same for spouse and adult-child caregivers, and higher (more satisfied with activities) for other relatives.

Results are contradictory, so comparison is difficult. Methods and measurements are different in each study. In the measurement of impact on schedule for this study, the items dealt more with perception of interruption of daily activities, and less time for relaxation, rather than actual activities in which a caregiver might wish to participate. Other variables that could affect perception of impact on schedule are the actual amount of involvement of caregiving, and the actual activities in which the caregiver was involved before the debilitation of the elderly person. In hypothesizing that the adult-child perceives more impact on schedule than the spouse caregiver, employment was considered to be a factor for impacting on one's schedule. Multiple regression, using the variables of caregiver employment, caregiver sex, and functional status of the elderly recipient, was performed. Employment (Beta .011, $\underline{p}$ = .843) was not significant, so possibly does not have an influence on perception of impact on schedule. An adult-child may perceive less impact on schedule because he/she may have more assistance (in staying with the impaired relative, so caregiver can socialize) from their spouse or children. The length of time of caregiving could have an affect on the results. That is an individual caring for someone for a short period of time might perceive an impact on schedule more so than when care becomes more of a routine. In this study, the elderly recipient of care shows more dependencies in PADL's and PMOBL's for the spouse caregivers, than the non-spouse caregivers, therefore, the spouses probably have more involvement in care. The findings in this study suggest that spouse caregivers perceive more impact on schedule than non-spouse caregivers.

Hypothesis VI: The spouse caregiver perceives greater impact on health status than the adult-child or other relative caregivers (child-in-law, siblings-in-law, others).

The hypothesis was accepted. A two-way analysis of variance was computed for a significance level of .001 (F = 20.938) so there was a significant difference in groups. The spouse mean (2.84) was higher than the non-spouse mean (2.45). The inference is that spouse caregivers perceive more impact on health status than non-spouse caregivers. This is expected since spouse caregivers are generally older, and thus, have more physical problems than the adult-child or others who are generally younger. Multiple regression was performed utilizing the variables of caregiver age, patient age, PIADL, PMOBL, and PADL with the result that caregiver age was significant (Beta = .118, p = .031) for impact on health.

Other research findings have agreed with the results in this study (Johnson & Catalano, 1983; George and Gwyther, 1986; Cantor, 1983). Measurements do differ in these studies in that respondents were asked to relate more objective findings, such as: (a) number of physician visits; (b) use of drugs; (c) impact of emotional and/or physical strain (0-2 no impact to great deal of impact); and (d) listing psychiatric symptoms. Perception of health status was usually not addressed.

<u>Hypothesis VII</u>: The spouse caregiver perceives greater impact on financial status than the adult-child or other relative caregivers (child-in-law, siblings- in-law, others.

The hypothesis was rejected. There was no significant difference between spouse and non-spouse caregivers (*F* = .170, *p* = .680). The results from studies are contradictory. Cantor (1983) documents that spouse caregivers reported a greater degree of financial strain than adult-child or other caregiver; but George and Gwyther (1986) were similar to this analysis that differences in perceived impact of economic status among spouse caregiver, adult-child caregivers, and other relative caregivers were not significant. In the sample for this study, finances might not be as pervasive an issue as other strains involved in caregiving, such as physical and mental strain, or impact on schedule because in general the respondents tended to be well educated and of a fairly adequate economic level.

<u>Hypothesis VIII</u> The spouse caregiver perceives more family abandonment than the non-spouse caregiver.

The hypothesis was rejected as stated.

There was a significant difference in means (*p* = .001) but the means were in a different direction than anticipated. The non-spouse mean (2.77) was higher than the spouse mean (2.37). Also, from the multiple regression analysis, there is an indication that non-spouses perceive abandonment either more or differently than spouse caregivers (family relationship Beta = -.244, $p$ = .000). Family relationship was coded as a dichotomus variable (1 = spouse, 0 = else). The unexpected is that non-spouse caregivers perceive more feelings of abandonment than spouse caregivers. The finding tends to be in disagreement with Johnson (1983) who found that in comparing with adult-child caregivers, spouse caregivers "provided the highest overall support with minimum help from other family members or providers" (p.380) The measurements were different in that more objective data were gathered in Johnson's study rather than perception of abandonment, as in this study. Worcester and Quayhagen (1983) documented that there was a positive relationship between caregiver's age and caregiver's satisfaction. They hypothesized that older caregivers may be more comfortable in the caring role than younger caregivers. If this is true, younger caregivers (usually adult children) may perceive more family abandonment than older caregivers (usually spouses) because the role is not expected, they have other family obligations, and they are not as comfortable in the caregiving role.

Another factor that may influence differences in groups is that caregivers are sometimes reluctant (or feel guilty) about answering questions that family members are not supportive. Reasons tend to be given by caregiver participants why individual family members are not supportive. Spouse caregivers may be more reluctant to answer questions that children are abandoning them, than non-spouse caregivers are about siblings or others assistance with a parent. The adult children in this study are mainly female (n = 94 from 101). Therefore, it can be interpreted that female adult-children perceive more family abandonment than spouse caregivers. The adult-child has competing demands such as child rearing, household responsibilities, job responsibilities (approximately 59 were employed), and she did not expect the caregiving role.

### Other findings regarding sex and family relationship variables

A two-way ANOVA analyses were performed for each dimension of perceived impact in comparing male and female as well as spouse and non-spouse caregivers. The only dimension in which there was an interaction between the two variables was impact on health. This can be interpreted that when the spouse/non-spouse category is controlled, sex of the caregiver does make a difference on the perception of impact on health. In this analysis the female spouse caregiver had the highest mean (2.98, $\underline{n}$ = 118). For the non-spouses, the male mean was higher (2.62, $\underline{n}$ = 11) than the female mean and the interaction was significant. (There were too few non-spouse males for the perceived impact on non-spouse males to be considered valid statistically.) Therefore, the affect sex has on the impact on health depends on whether the caregiver is a spouse or non-spouse. The inference is that female spouse caregivers are probably more at risk for health problems than other female caregivers of a different family relationship. Also, the male spouse caregivers in the study may be healthier than the female spouse caregivers. The findings are congruent with Fitting et al. (1986) and Zarit et al. (1986) who studied the differences between male and female spouse caregivers.

For impact on schedule, the results from the two-way ANOVA could suggest that family relationship ($p$ = .015) has more affect in that domain than the sex of a caregiver. Johnson (1983) and Zarit et al. (1986) found that husbands experience less strain than wives as caregivers.

Perception of financial impact may not be as much of a concern as other issues of caregiving, since there were no significant differences in both the one-way and two-way ANOVAS. The female spouse mean was higher (2.60, $n$ = 118) than the male spouse mean (2.45, $n$ = 39), but not significantly. The mean was higher for the non-spouse male (2.64, $n$ = 11) compared to the non-spouse female (2.52, $n$ = 135). There were only 11 non-spouse males, but they possibly spend more for services to care for the elderly person. The inference (even though there is no significant difference) is that female spouses and male non-spouses perceive more financial impact than male spouses and female non-spouse caregivers.

In regards to perception of abandonment, family relationship was significant (non-spouse had a higher mean, 2.77, _n_ = 146, than spouse caregivers, 2.37, _n_ = 157). There does not appear to be a relationship or interaction between sex and family relationship. Family relationship may have an affect on perception of abandonment, but whether the relative is male or female does not make a difference. (The female spouse mean was higher, but not significantly in the two-way ANOVA).

Few studies were found on perception of abandonment and the statistical analysis of the interaction of sex and family relationship are not addressed. Johnson (1983) documents that male spouse caregivers have more frequent contact with children and other relatives and use more formal providers than female spouse caregivers (chi-square). Snyder and Keefe (1985) concurred that male caregivers utilized more formal services than female caregivers. The findings in this study indicate that male spouses perceive less abandonment, but since there were so few non-spouse males, it cannot be shown that all male caregivers perceive less abandonment. Therefore, there is a slight inference that there is a perception of less abandonment among male caregivers than female caregivers. Females are expected in our society to act in the caregiving role more so than men.

Socioeconomic status

In the next group of hypotheses, multiple regression analyses were performed on spouse and non-spouse caregivers separately because of the separate recording of income for both groups. Caregivers sex and family relationship were added to the equation along with functional status of the elderly person (PADL, PIADL, and PMOBL) to determine if there was a relationship between the functional level of the elderly person and the affect of the caregiver characteristics on the impact of caregiving.

Hypothesis IX: Caregivers in the higher socioeconomic level (income and education) perceive less impact on schedule than those in the lower socioeconomic level.

The hypothesis was rejected for both spouse and non-spouse caregivers in that the variables of spouse income, spouse educational level, non-spouse caregivers' income, and patient income were not significant in the multiple regression analysis.

The rejection of this hypothesis tends to disagree with Archbold (1982) who found that caregivers with lower income ($7,0000 - $9,999) had to adhere to a rigid schedule (20% of 15 caregivers were employed), whereas those in a higher income level ($15,000 - $19,999) used more community resources and services. Using community resources and services may increase the perception of impact on schedule because a family member has to arrange and coordinate the services. The findings in this study could reflect the fact that the sample population was fairly well-educated and reported fairly adequate incomes so there is not a sufficient comparison between those with marginal incomes and those with higher incomes. Also, the difference in socioeconomic levels may have no affect on caregiver's perception of impact on schedule, in that items (in the study) regarding the domain of schedule are not focused on any financial concerns.

In regards to the elderly person's functional status, there were negative correlations between spouse income and PADL's (-.111) and PMOBL's (-.127) and caregiver income (non-spouse) and PADL's (-.203) and PMOBL's (-.189). The functional status was significant in both groups of caregivers. Therefore, the functional level of the elderly person can be a factor in the perception of impact on the caregiver's schedule, regardless of the socioeconomic level. Paulshock et al. (1984) found that ADL impairment of the elderly person was highly correlated with caregiver's social activity restrictions (r = .45).

<u>Hypothesis X</u>: Caregivers in the higher socioeconomic level (income and education) perceive less impact on health status than those in the lower socioeconomic level.

The hypothesis was rejected through the multiple regression procedure. In analyzing spouse caregivers, the spouse income, spouse educational level (indicators of socioeconomic status) were not significant. Non-spouse caregiver income, patient income, and non-spouse educational level were not significant when the non-spouse caregivers were analyzed. The directions of the Beta coefficients for the variables of spouse income, spouse education, non-spouse education, and patient income were negative. There is an inference that caregivers in the higher socioeconomic level perceive less impact on their health status. There were no studies with which to compare results. An indication from the inference is that those in the higher socioeconomic level may have the resources to utilize more health care or preventive health measures, than those in the lower socioeconomic level.

Interestingly, The elderly person's PIADL's, when analyzing the spouse caregiver, was the only significant functional level variable in the dimension of health. In the non-spouse caregivers, none of the functional variables of the patient (elderly person) were significant. The PIADL is not a good measure for this sub-sample because of the lack of variability (n = 196, or 63.8% patients had dependencies in six PIADL's).

From the results (no statistical significance) in these analyses, the socioeconomic level and the functional level of the elderly person does not have affect on the perception of impact on health status. The findings regarding the elderly person's functional level agree with Hawranik (1985) and Fitting et al. (1986), but disagree with Snyder and Keefe (1985) and Sushil (1985) who indicated that the impairment and illness of the elderly person has an effect on the likelihood of caregiver reporting health problems.

Other factors for this sample might have influenced the results, such as the caregivers actual health status, other measurements of functional level, and length of time of caregiving.

Hypothesis XI: Caregivers in the higher socioeconomic level (income and education) perceive less impact on finances than those in the lower socioeconomic level.

The hypothesis was partly accepted for spouse caregivers ($p$ = .001) but was rejected for non-spouse caregivers through the multiple regression analysis. Spouse income was significant, but spouse education was not significant. The finding tends to be congruent with Cantor (1983) who documented that spouses reported a greater degree of financial strain than adult-child caregivers or other relative caregivers, but Cantor's measurements were not the same as in this study. George and Gwyther (1986) found that spouse caregivers reported a significantly lower income than adult-child caregivers, but they did not address if caregivers perceived that they had adequate income in regards to providing care. Again, there is an inference that non-spouse caregivers in the lower socioeconomic level perceive more impact on financial status (negative Beta coefficients for non-spouse caregiver income, education, and patient income) than the non-spouse caregivers in the higher socioeconomic level. According to the two-way ANOVA procedure, there is little difference in the perception of financial impact between spouse and non-spouse caregivers.

The functional level of the elderly person was not significant in the financial dimension, even though there was a correlation between: (1) finance (dependent variable) and PADL (.247) and PMOBL (.234); (2) spouse income and PADL (-.112) and PMOBL (-.129); (3) finance (non-spouse) and PADL (.141); and (4) non-spouse caregiver and PADL (-.203). Therefore, functional status of the elderly recipient of care may not influence the caregiver's perceived impact on finances (regardless of socioeconomic status), even though more impairment for the recipient of care may result in increased spending for supplies and equipment. The lack of significance of the elderly person's functional status in regards to financial impact may be a reflection that the sample for this study is generally well-educated and has some economic resources. In the situation of adult children, the elderly person's income may be utilized for supplies, equipment, and other medical needs.

<u>Hypothesis XII</u>: Caregiver in the higher socioeconomic (income and education) level perceive less abandonment than those in the lower socioeconomic level.

Through multiple regression analysis, the hypothesis was partly rejected for spouse caregivers, (spouse income $\underline{p} = .047$) as stated. It was entirely rejected for non-spouse caregivers. The unexpected direction was that the higher the spouse income, there was more perceived abandonment. The caregiver educational level was not significant for either group. There were negative Beta coefficients for caregiver education and patient income (non-spouse) even though spouse and non-spouse incomes were positive in direction. The researcher does not have an explanation for the different inferences. There are no studies with which to compare.

Worcester and Quayhagen (1983) reported from their study that lower income persons show slightly more satisfaction with the caregiving situation than higher income persons. Once again, that is a global rating and the study did not address the dimension of abandonment. The fact that spouse income is a significant variable may suggest that socioeconomic level does have some impact in perception of abandonment. The explained variance in the dependent variable (abandonment) resulting from the combined influence of spouse income and other variables ($R^2 = .076$) is so small that other factors must cause differences in perceived abandonment (true by definition unless $R^2 = 1.0$).

In the area of abandonment, it was hypothesized that caregivers who receive more assistance would perceive less abandonment. The hypothesis was made in order to give some explanation to the dimension of abandonment. Frequency of help was significant in that the less times persons assisted, there was more perceived impact from abandonment. These findings help explain some effects on the particular domain, but still doesn't answer all the influences on caregivers who perceive abandonment. In the same multiple regression equation, caregivers sex (female) was significant and family relationship (non-spouse) was significant, thus, the results were the same as the one-way and two-way ANOVA, even with other variables added.

The functional status of the elderly person was not significant in the dimension of perceived abandonment for either the spouse or non-spouse caregivers. Scott et al. (1986) found evidence of family support in a study of caregivers of Alzheimer's patients (though the sample was small ($N$ = 23). Possibly caring for a more disabled elderly person brings a family closer together; or the degree of impairment of the elderly person makes no difference in perception of abandonment.

Other findings

As can be noted from Tables 5.8, 5.9, 5.10, and 5.11, caregivers sex was added to the multiple regressions equations. In the schedule, health and abandonment domains, the variable of caregiver sex was significant for spouse caregiver. The schedule area was the only dimension that the statistical significance of sex changed when functional status was added to the analysis. This can lead to the assumption that functional status of the elderly person does not affect the difference in perception of impact on health or abandonment by sex, but the functional status may have some influence on how a male or female spouse caregiver perceives impact on schedule.

## Summary

A summary (refer to Table 5.13) of the findings are as follows:

1. The hypotheses that female caregivers perceive more impact on the dimensions of schedule, and finances were rejected.
2. The hypotheses that the female caregiver perceives more impact on health and from family abandonment were accepted.
3. The inferences are that female spouse-caregivers perceive more impact on schedule, health, and feelings of family abandonment than the male spouse caregivers. There was no significant difference between male and female spouse caregivers in the perception of impact on financial status.
4. There was no significant difference between male and female non-spouse caregivers in all of the dimensions (schedule, health, finance, and abandonment). The male sample was probably too small for a legitimate analysis.

5. The hypothesis of the adult-child and other relatives perceiving more impact on schedule than the spouse caregivers was rejected (spouses were significantly higher).
6. The hypothesis that the spouse caregiver perceives more impact on health status than the non-spouse caregiver was accepted.
7. The hypothesis that the spouse caregiver perceives more impact on financial status than the non-spouse caregivers was rejected.
8. The hypothesis that the spouse caregiver perceives more family abandonment than the non-spouse caregiver was rejected. (The non-spouse was significantly higher.)
9. The hypotheses that caregivers in the higher socioeconomic level perceive less impact on schedule and health was rejected for both spouse caregivers and non-spouse caregivers. In the dimension of finance, the hypothesis was accepted for spouse caregivers, but was rejected for non-spouse caregivers. In the abandonment domain, the unexpected inference is that those in higher socioeconomic status perceive more abandonment.
10. Caregivers who receive more family/friend assistance may perceive less family abandonment than those with less assistance from family/friends.

11. In regards to functional status of the elderly person:
    a. Through multiple regression, the PADL's and PIADL's were statistically significant in the schedule dimension. Therefore, functional status may have an affect on the perception of schedule impact for male or female caregivers.
    b. In performing multiple regression, PADL, PIADL, or PMOBL were not significant in the dimensions of finance or abandonment for spouse and non-spouses. PIADL's were significant for health. Caregiver sex (spouse) was significant, but the functional status variables do not appear to explain the differences in perception of impact by sex.

In Chapter VI, the recommendations and conclusions from the study will be presented. Implications for nursing practice, nursing education and further research will be discussed, along with Orem's theory in nursing.

Table 5.13: Hypotheses Acceptance or Rejection, and Significance

| | Hypotheses | Accepted +<br>Rejected - | Significance |
|---|---|---|---|
| I. | The female caregiver perceives more impact on her schedule than the male caregiver. | - | P = .165 |
| II. | The female caregiver perceives more impact on health than the male caregiver. | + | **P = .008 |
| III. | The female caregiver perceives more impact on financial status than the male caregiver. | - | P = .612 |
| IV. | The female caregiver perceives more family abandonment than the male caregiver. | + | **P = .007 |
| V. | The spouse-caregiver perceives less impact on schedule than the adult-child and other relative caregivers (child-in-law, siblings-in-law and others) | - | *P = .015<br>(spouse mean higher) |
| VI. | The spouse caregiver perceives greater impact on health status than the adult-child or other relative caregiver. | + | ***P = .000 |
| VII. | The spouse caregiver perceives greater impact on financial status than the adult-child or other relative caregivers (child-in-law, siblings-in-law, and others). | - | P = .690 |

Table 5.13 (continued)

| | Hypotheses | Accepted +<br>Rejected - | Significance |
|---|---|---|---|
| VIII. | The spouse caregiver perceives more family abandonment than the adult-child or other relative caregivers. | - | ***P = .001 (non-spouse mean higher) |
| IX. | Caregivers in the higher socioeconomic level (income and education) perceive less impact on schedule than those in the lower socioeconomic level. | - | P = .743 spouse income<br>.253 education<br>P = .600 caregiver income<br>.629 patient income<br>.781 education |
| X. | Caregivers in the higher socioeconomic level (income and education) perceive less impact on health status than those in the lower socioeconomic level. | - | P = .653 spouse income<br>.628 caregiver education<br>P = .800 caregiver income<br>.409 patient income<br>.118 education |
| XI. | Caregivers in the higher socioeconomic level perceive less impact on finances than those in the lower socioeconomic level. | + | ***P = .001 spouse income<br>.903 education<br>P = .100 caregiver income<br>.358 patient income<br>.119 education |
| XII. | Caregivers in the higher socioeconomic level perceive less family abandonment than those in the lower socioeconomic level. | - | *P = .047 spouse income<br>.962 education<br>P = .491 caregiver income<br>.379 patient income<br>.958 education |

*P $\leq$ .05
**P $\leq$ .01
***P $\leq$ .001

# Chapter VI

# SUMMARY AND CONCLUSIONS

## Overview

A descriptive design based on data from a cross-sectional survey was used for this study. The relationship of certain caregiver characteristics were analyzed as to their affect on the caregivers' perception of impact on their schedule, health, finances, and feelings of abandonment. The research question was: "How are selected caregiver characteristics related to perception of burden?" The interpretation and summary of the results were given in Chapter V. The limitations of the study and implications for nursing practice, nursing education, and research will be outlined in this chapter.

## Limitations of the Study

While the sample for this study was large (N=307), there are a few limitations to the research. Respondents in the sample (caregivers and elderly recipients of care) were predominant Caucasian (92.2%) and also were fairly well educated. The subsamples were very small or disproportionate. These characteristics make generalization of the findings difficult. Perception of impact from caregiving may be different in other ethnic groups and less educated groups. The size of the sample, though, adds strength to the analysis. In further studies, other ethnic groups should be analyzed to compare results.

Another limitation is that this was not a probability sample, which would have been more representative of the population. The results can only be generalized to the actual population studied. Also, since the sample was non-random, inferences can be made rather than definite statistical conclusions. Individuals volunteered for the research, thus, their perceptions might be different than those who did not volunteer. The individuals participated in the study because they met the criteria of being a caregiver. One cannot assume that the caregivers were similar at the beginning of investigation. Previous conditions or situations in the caregivers' lives may be the explanation for differences in the dependent variables of perceived impact on schedule, health, finances, and abandonment.

When participants enrolled in the study, each had been providing care for different lengths of time. The number of weeks, months, or years of caregiving can affect the perception of impact from caregiving. It is also difficult to assess the personal relationship between caregiver and elderly recipient of care. Perceived impact from caregiving can be affected by the type of interpersonal relationship between individuals of the caregiver-recipient dyad.

The respondents had to be literate in order to complete the questionnaires. Others less educated or illiterate would be excluded because of the complexity of the study. The final limitation is that the age of the care-recipient was limited to those over 64 years of age. This criteria eliminated the younger impaired adults being cared for by family members. There might be differences in perceptions of burden between caregivers of the older impaired adult and those of the younger impaired adult.

### Conclusions and implications from research

In Chapter II the model for the caregiver study was presented. The characteristics of sex, socioeconomic status and relationship of the caregiver to the elderly person was shown as affecting the perception of each dimension (schedule, health, finances, and abandonment). As was presented in the hypotheses (Table 5.13), each of these characteristics have significance in certain domains, but not in all of the dimensions of impact. For example, there is a suggestion from the data that there is a difference in the perception of feelings of abandonment between the male and female caregiver. This difference could be an implication (not a cause-effect relationship) that the female perceives more feeling of family abandonment than the male, but there needs to be more research.

From the analysis of the entire sample there is an indication that there are no differences between male and female caregivers in their perception of impact on schedule, health, and finances. Therefore, the sex characteristics may be important to consider in the dimension of abandonment, but not in the other dimensions. In analysis of the spouse and non-spouse caregivers separately, there appears to be a relationship between the sex of the spouse and the perception of impact on schedule, health, and feelings of abandonment, but not with perception of impact on financial status. Sex can be a factor in perception of impact on certain dimensions regarding spouse caregivers. There were not enough non-spouse males for the results of the analysis between males and females to be statistically practical.

Caregiving continues to be primarily a role of women. Even though women's roles are changing, that is more women may be career oriented or at least working, our culture still reflects the fact that caregiving is an appropriate activity for women, rather than men.

In the perception of abandonment, there is more impact for female than male caregivers. The reasons could be that: 1) women do not receive as much support because they are expected to care for a spouse or parent; 2) men are less often involved in "hands on care" (personal care, meal preparation) than women and are not as involved in such time-consuming tasks; 3) a female adult-child caring for a parent may have the competing demands of work and family, and provide emotional support to their own family and elderly parents more so than men; 4) female adult-children might receive less assistance from a husband, whereas a male adult-child may receive assistance from his wife, as expected in our society; 5) women may have more difficulty than men keeping an emotional distance, either from their spouse or parent, which is necessary to consider alternative strategies (Zarit et al., 1986); 6) men are used to the delegation of responsibilities and recognition of their own limitations from participating in the work world (Fitting et al., 1986); and 7) coping skills of women may differ from men. The reasons listed may influence a female's sense or perception of abandonment - she feels alone.

Possible reasons for differences in perception of abandonment by males and females was addressed. There was also an inference from the study that female spouses perceived more impact on schedule, health, and abandonment than male spouse caregivers.

The female spouse's perception of impact on her schedule may be a result of an interruption of a more leisure life-style since completing child raising, or possibly job responsibilities. She is less likely to be able to participate in activities and visit with friends since assuming the role of caregiving. The female spouses in the study may have been providing care for more functionally impaired mates than the male spouse-caregivers. According to Fitting et al. (1986), "a male caregiver who had defined his life in terms of his occupation was now in a new 'provider' role helping his spouse with activities of daily living" (p. 251). The husband may not perceive an impact on schedule because he assumed another occupation in place of his earlier career. Also, as mentioned earlier, male caregivers may be able to delegate some responsibility easier and, thus, have some freedom from caregiving responsibilities.

It is difficult to assess why female spouse caregivers perceive more impact on health than male spouses because both groups are aging and, thus, have possibilities of chronic illness or decreased strength. There is a possibility that the male spouse caregivers in this study were healthier. Also, in our society, males do not tend to admit to health problems as easily as women. It can be difficult for a man to admit that he does not have enough physical strength or that his health has become worse. The care recipient of the female spouse may be more dependent than those of the male-spouse caregivers; thus, the female has more caregiving involvement and becomes tired or perceives changes in health. Reasons for abandonment, as mentioned earlier, may include: 1) the female spouse receives less support from others because caregiving is an expected role for women; 2) the male spouse provides less personal care, in that other women in the family may assist with the care; 3) female spouses have more difficulty in keeping an emotional distance from their mate; and 4) the male spouses utilize more formal service than the female spouse.

Implications from the findings thus far, are that interventions need to be focused on female caregivers, particularly in the dimension of abandonment. Programs that offer more supportive assistance in the home are needed. Home health programs are either too expensive for some caregivers or the criteria for coverage, as outlined by insurance or Medicare, are so restrictive that many families cannot be included. Also, the coverage is only for short periods of time. Allowances need to be made for caregivers who provide care to an impaired elderly person for long periods of time, sometimes years. Women caregivers need special attention and support to help with decision making and problem solving regarding caregiving. Also, possibly the female caregiver may need support in asking other family members for help. Programs of respite care, one-night relief, and temporary care to ease the caregiving task would help not only the female, but any caregiver to perceive less abandonment. Support groups for women can be very effective in helping the female caregiver to feel less alone. Strategies of caregiving can be shared. Women usually are more attuned to support groups than men.

Respite programs, adult day care programs, and home health assistance can help lessen the impact on schedule for the female spouse caregiver, if there is a coordination of activities. Care management is needed because services can be fragmented and the coordinating of different services can be time consuming and difficult.

In regards to the perceived impact on health by female-spouse caregivers (others have perceived impact on health, but indication from this research is that female-spouse caregivers perceive more impact than male-spouse caregivers), services should be available in order to ease the caregiving tasks. Overnight services outside of the home, personal care and/or other services for in-home help, such as meal preparation, shopping, and transportation, are all needed so that the caregiver may have some relief, therefore, less strain. If the caregiver becomes exhausted, he/she may be responsible for elderly abuse, he/she has to admit the elderly individual to an institution, or he/she suffers from severe deterioration in health.

The relationship of the caregiver to the elderly recipient as a characteristic varies according to the dimensions of impact from caregiving. There was a significant difference between spouses and non-spouse caregivers in perceived impact on schedule, perceived impact on health, and perceived family abandonment. There is an indication that spouse caregivers perceive more impact on schedule and health than the non-spouse caregivers, and the non-spouse could perceive more impact from family abandonment than the spouse caregiver.

The higher perceived impact on schedule by the spouse caregiver than the non-spouse caregiver can be explained by the fact that the caregiver lives alone with the debilitated person, so has no one accessible to stay with the patient for relief. Also, the spouse caregiver in this study might be providing care for a more functionally impaired person, so experiences more caregiving involvement than the non-spouse caregiver. Therefore, there are more interruptions in activities, or less free time. The implications are the same as mentioned earlier, that policies are needed to increase in-home relief service, respite care, adult day care, and a case management program to assist in coordinating services.

The spouse caregivers perceive more impact on health than non-spouse caregivers because the spouse caregivers are older and are more likely to be suffering from chronic disease problems themselves. Here again the strain could be relieved by increased services so the caregiver may have some relief and time to themselves. If services are too expensive, the caregiver will not utilize them. The Medicare and Medicaid programs could relieve the strict criteria for in-home assistance. A self-care support group would be beneficial for promoting better health and wellness.

From the analysis, there is a suggestion that the non-spouse caregiver (who is usually female) perceives more family abandonment than the spouse caregiver. The reasons for differences in perception of abandonment between the spouse caregiver and the non-spouse (mostly adult-child in this study) caregiver is: 1) the adult child may be overwhelmed with all of the responsibilities of caregiving, plus running a household of her own; 2) the role of caregiving is not an expected role at this time in his/her life; 3) siblings may be less likely to assist with care for a parent, or there may be disagreements over how care is provided so the adult child does not receive support; and 4) the adult child is usually female, and as mentioned several times, her spouse may give little assistance because it is an expected role of the female and not of the male.

The implication is that the non-spouse caregiver needs support services, if not from family and friends, then from formal services. A support group would be helpful in order to share concerns and strategies and, thus, the caregiver would feel less abandoned in dealing with the problems and concerns of providing care to an elderly patient.

Lastly, there is a suggestion from the results of this study that family relationship is more important as to its affect on perceived impact from caregiving than sex of the caregiver. The implication is that there needs to be a focus on programs (mentioned earlier) to help reduce perceived impact on schedule and health for spouses, and a focus on programs to reduce perception of family abandonment for adult children. The family members usually identified as the caregiver are, first, the spouse, where one exists, then the daughter. These groups need assistance to prevent exhaustion and burn out of the caregiver.

The socioeconomic status of the caregiver appears to have little affect on perceptions of impact from caregiving except in the financial and abandonment dimensions. The relationship between socioeconomic status (income and education) and impact on financial status might be a natural assumption without the process of analysis. Actually spouse income, not education, were significant in the domains of finance and abandonment. Those individuals in a higher socioeconomic level perceive less problems with finances than those in the lower socioeconomic level. There is no explanation why those in the higher socioeconomic level perceive more abandonment; unless those in higher economic levels are more involved with activities and business affairs so give less support to family caregivers. Other problems of caregiving might be more of a pervasive issue than finances such as impact on schedule and health. The variable of socioeconomic status might not be appropriate or important to analyze in the future.

The entire sample of caregivers was measured for perception of impact for each dimension of schedule, health, finance, and feelings of abandonment. It appears that impact on schedule is perceived to be greater than the impact on health, finance, and abandonment. So again, support is needed for programs of care management, respite services, and in-home help.

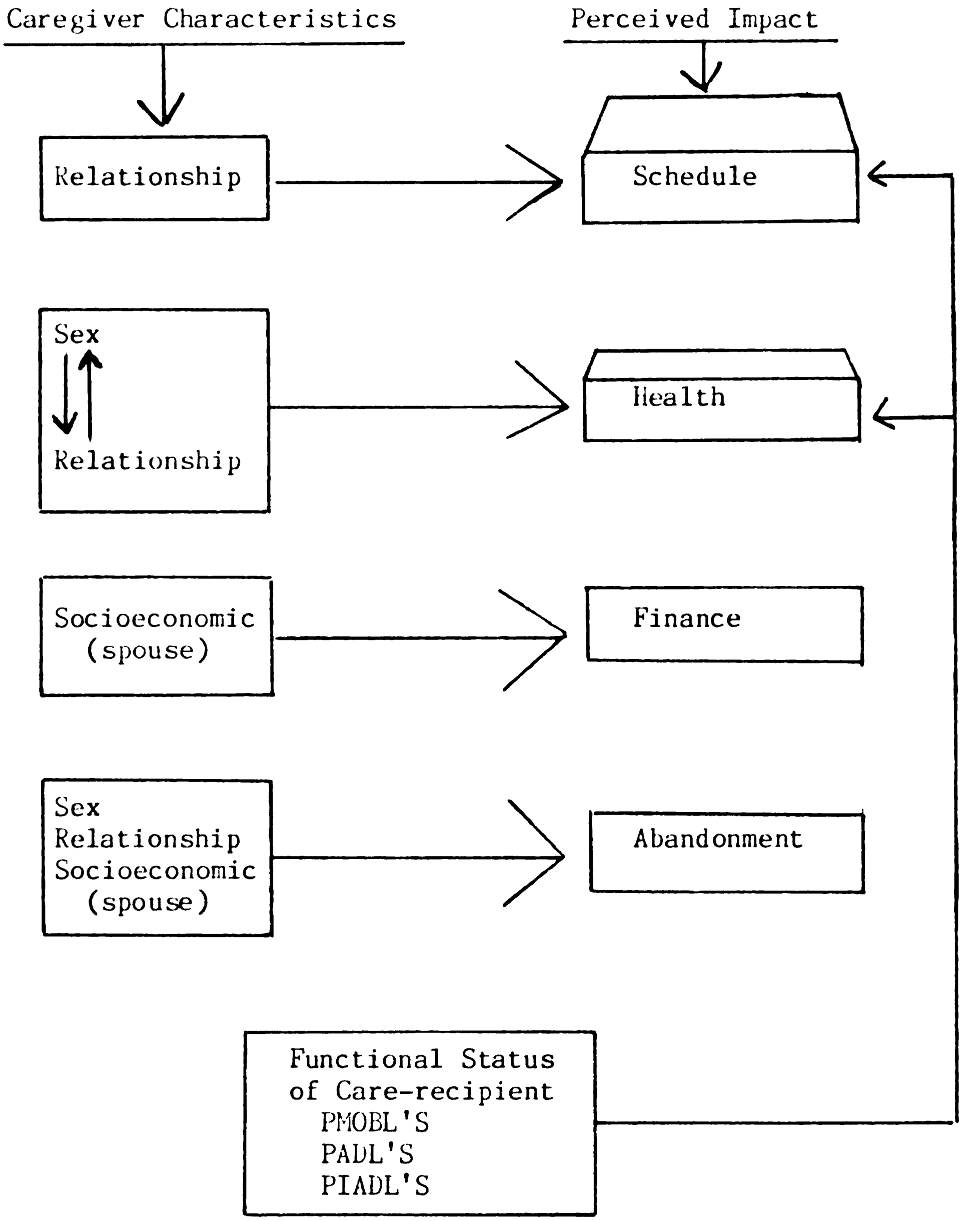
As derived from this research (the functional status of the elderly person (measured by PADL's, PIADL's, and PMOBL's) did not affect the perceived impact in the financial domain or family abandonment. In the dimensions of schedule and health, the functional status, particularly PADL's and PMOBL's, were more important than other independent variables such as caregiver sex for the spouse caregiver in the dimension of schedule. For non-spouses, in the dimension of schedule, the only significant variable was PMOBL's. For the dimension of health, the PIADL variable was higher (from Beta) in relative importance than caregiver sex (spouse-caregiver). The PIADL probably was not an adequate variable since there was not much variability in the sample for these activities. Therefore, from the results of this study, functional status does not appear to make a difference in the perception of the two dimensions of finance and and family abandonment. The severity of the impaired elderly person possibly has an affect on the perceptions of impact on schedule and health particularly for the female spouse caregivers. In Figure 3, the findings from the study are presented.

## Implications for Nursing Practice

There are implications for nursing practice from this study. Orem's (1980) theory of self-care will be used in understanding the application of the nursing process for the caregiver.

Orem (1980) states "that self-care is the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health, and well being" (p. 35). Orem's philosophy is that people have the innate ability to care for themselves. The innate ability to care for one's self could be a limitation in Orem's theory in the sense that if you can participate in self care, why is the assistance of a nurse necessary. Orem focuses on an individual being ill or injured. Therefore, when an individual is ill or not functioning normally, he/she needs assistance and/or instruction in self care. The eight self-care requisites according to Orem include the maintenance of a sufficient intake of air, water, and food; the provision of care associated with the elimination of processes and excrement; a balance between activity and rest; a balance between solitude and social interaction; and the promotion of human functioning and development in accord with human potential, known human limitations, and the human desire to be normal (Orem, 1980). When problems occur and interfere with one's ability to meet these universal self-care

Figure 3. Graphic Presentation of Findings



demands, other people (such as nurses) must become involved for assistance and support. The role of nurses at this point, is to assist the individual (such as the caregiver) to meet the universal self-care demands. The requirements of Orem's theory are important for the caregiver, in that the caregiver can better perform the caregiving role if he/she is emotionally, mentally, spiritually, and physically well. Even though the age, sex, or relationship of the caregiver to the elderly person may affect his/her perception of providing care, the impact could possibly be lessened if the caregiver is well.

Orem (1980) describes three nursing systems: (1) wholly compensatory - the patient has no active role in performance of care; (2) partly compensatory - the patient can perform a few self-care actions; and (3) supportive-educative - the patient performs self-care. The caregiver would be placed in the supportive educational system because the caregiver needs guidance and emotional support. He/she may require instructions on caregiving skills, may need to be referred to a self-help support group, and may need assistance with developing strategies for caregiving from the clinical nurse specialist (CNS). The CNS also must promote interactions so trust can be developed between the CNS and caregiver. The caregiver has the potential for being able to focus on her or himself, to care for another individual, and to make reasonable judgments and decisions about daily living through the CNS giving guidance, direction and providing support.

In Figure 4, a model has been adapted from Orem's model on demonstrating a nursing focus of a particular health situation. Since this study is mainly exploring a caregiver's perception of burden or impact, the patient or recipient of nursing intervention is mainly the caregiver. The elderly person will be included in the model, because his/her impairment could have an affect on the caregiver's perception of impact in some dimensions such as schedule and health. In reality, the nurse CNS (clinical nurse specialist) would intervene both with the caregiver and the elderly patient.

In the model, it is demonstrated that the CNS must develop a perspective of the caregiving situation, such as caregiver's ability to provide care, any disabilities that might hinder care (both caregiver and elderly person) and caregiver's health; also, what has to be done to help the caregiver to perceive or feel less impact from caregiving. At the same time, the nurse must consider how the caregiver views and is affected by the situation of providing care.

The CNS needs to be aware of the focus on the perceived impact in the dimensions of schedule, health, and abandonment for the female spouse. The CNS also needs to be aware that the non-spouse (most likely adult-child) tends to perceive abandonment more so than the spouse caregiver. The nurse's recognition and acceptance of the caregiver's perspective is essential for the nurse to receive caregiver's cooperation, to develop mutuality, to help the

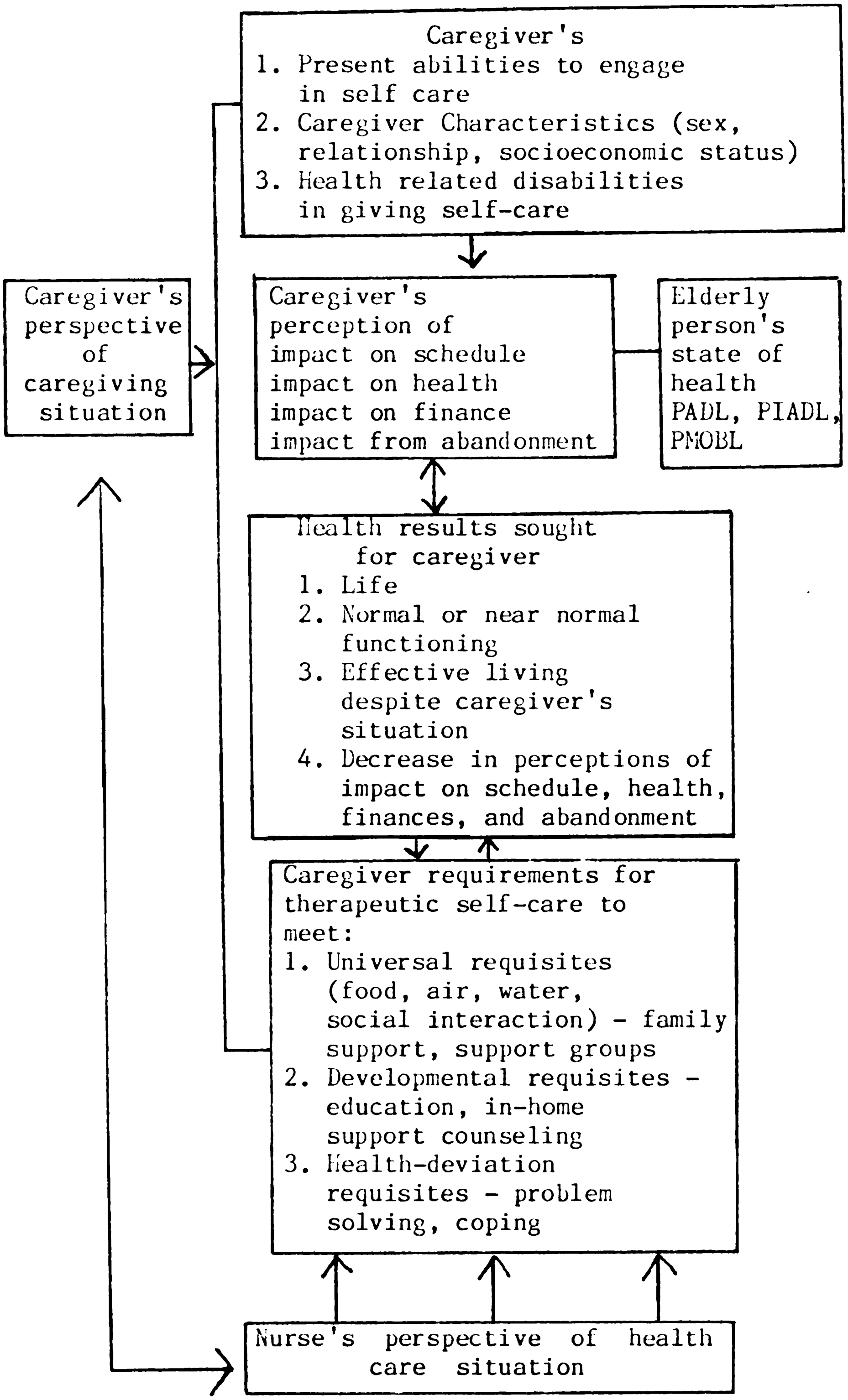


Figure 4: Nursing Model
Reproduced by permission from Orem, Dorothea E.: Nursing: concepts of practice, ed. 3, New York, 1985, McGraw-Hill Book Co.; copyrighted by The C.V. Mosby Co., St. Louis.

caregiver feel motivated to try strategies, and to properly refer the caregiver.

The box for nursing intervention is used to show that after the nurse and caregiver have developed a perspective on the situation and agree about the situation, strategies can be developed. The result would be that the caregiver would feel less impact from the role of caregiving, or the caregiver may develop the ability to cope. Possible type of intervention (as shown in Figure 4) could be referrals and utilization of community agencies, problem-solving technique, referral to support group, education, and allowing verbalization of feelings.

In the dimension of abandonment, the CNS in primary care should assess the caregiver's expectations of support from family or friends; the CNS should also assess if the family has been supportive in other crisis or difficult situations. The CNS could convene a family meeting to gather an understanding of other family members' concerns and the family members knowledge of the elderly person's disability. Types of assistance that could be helpful to the caregiver could be addressed. The CNS could suggest frequent visits. This and social support from others are helpful in preventing feelings of abandonment. This type of intervention (family conference) would only be accomplished after developing some support and trust with the caregiver. Also, a function of a clinical nurse specialist in primary care would be to find acceptable respite services or in-home help, and also teach and describe the accessibility of the services to the caregiver. The teaching, regarding access to services, reinforces the fact that the caregiver is in the supportive-educative system of Orem's theory. The other function for a CNS in primary care, in trying to lessen the impact of abandonment, would be to offer or refer the caregiver to a support group. In the caregiver support group, strategies and problems can be shared. The caregiver would feel less abandoned. Lastly, the CNS needs to provide continuity, by monitoring for changes in the caregiving situation so the caregiver does not perceive abandonment by a professional.

Case management could be a function of the CNS, at the primary care site, in helping alleviate a perceived impact on schedule. Services (respite care, adult day care, in-home help) in communities are fragmented and overlapping in assistance offered. Many contacts have to be made in order to assess which service is appropriate for the caregiver. A CNS could make the contacts. describe them to the caregiver, and coordinate the services. Thus, the caregiver would have some free time being able to enjoy some activities, visit some friends, plus enjoy some relief from constant caregiving. The dimension of schedule appears to be the domain with the most perceived impact in this study. The CNS should verbalize the potential of impact on schedule to the caregiver, and strategies utilized by others so that the caregiver is more aware that this happens with others. Some caregivers at the beginning stages of caregiving may not perceive this as happening. Anticipatory guidance can be provided by the CNS. Again, family support can be helpful in allowing the caregiver to have some leisure time.

In the health dimension (which is the second highest perceived impact in this study) particular focus should be given to the spouse caregiver by the CNS in primary care. If possible, the CNS should promote self care, as defined in Orem's theory. If the caregiver is well, he/she is better equipped to cope and handle providing care to an elderly family member. An emphasis should be placed on proper exercise and diet, and time for themselves. The CNS must assess for signs and symptoms of increased fatigue, and/or change in health status. A professional such as a CNS reinforces that the caregiver should enjoy free time, participate in an exercise program, and visit a doctor as needed. The caregiver might need the permission from a CNS. In other words, the caregiver does not feel so guilty participating in other activities if a CNS reinforces this is needed. Female caregivers, in particular, may tend to feel guilty more so than male caregivers.

Females may need help to learn how to delegate responsibility (if others are available), so that they are not over burdened by the task of caregiving. Also, the CNS must teach proper caregiving skills which might make it easier to provide care for the patient. As in the other dimensions, the CNS can describe and refer respite services, in-home help, chore providers, transportation services, overnight services outside the home, collaborate with the caregiver's physician who might relieve the caregiver, thus, promoting wellness and health.

By the nurse practicing Orem's theory, that people have the ability to care for themselves, he/she can accept the caregiver's perspective of the situation; and through mutuality help the caregiver to initiate activities that help maintain life, health and well-being. Therefore, the impact on the caregiver's life from providing care to an elderly person might be lessened.

Keeping in mind the perception of impact from caregiving, the CNS in primary care can assess the caregiver's physical status, psychosocial status, and spiritual status. The CNS could possibly utilize such scales as the Beck Depression Scale (1961) as an awareness tool for the caregiver, the Ireton Personal Inventory (1979), or possibly use the questionnaire items in each dimension of this study as a screening tool. Answers to these items make the caregiver more aware of his/her feelings and also give the CNS a perspective of the caregiver's strengths and weaknesses. The CNS needs to assess the past experiences of the caregiver, including any caregiving roles in the past, plus the personal relationship between the caregiver and the elderly recipient of care. These assessments provide a better understanding of the caregiving role for both the caregiver and the CNS. The CNS in primary care as a counselor can provide a stabilizing human support relationship. The caregiver can feel free to express concerns and frustrations. Thus, a relationship of mutuality can be developed in order to facilitate care of the impaired elderly person, enhance the well being of the caregiver.

The caregiver and the CNS can begin problem solving and attaining goals together. From results in this study, the CNS needs to focus on: 1) the female caregiver, who possibly perceives more family abandonment than the male caregiver 2) the female spouse who appears to perceive more impact on schedule, health, and abandonment than the male spouse; 3) the fact that the spouse may perceive more impact on schedule than the non-spouse; and 4) the non-spouse may perceive more family abandonment than the spouse. The CNS should assess and attempt to utilize either family members or community agencies for support for the caregiver. From the indications from this study, the CNS can utilize the knowledge at the primary care site to counsel the caregiver using anticipatory guidance and giving support. For example, the CNS can prepare the female caregiver that she might feel abandoned. Once the care provider is aware of such a possibility (abandonment), he/she and the CNS can begin to focus on possible support systems to lessen the feelings of abandonment. This is also true for the female spouse regarding perception of impact on schedule, health, and abandonment. The CNS can give an objective analysis of the situation.

## Implications for Nursing Education

The elderly are living longer in our society. Their problems are multiple, chronic, and long term. The major share of support and care for the older individual is provided by the family. It is important that nursing students understand the implications of caring for an elderly individual at home, sometimes for many years. Curriculum on geriatric care and on the physiological and psychological changes in aging would provide an understanding of the elderly person.

Curriculum in the past has included nursing care of clients without differentiating the pathophysiological and psychological changes in aging from the younger clients, thus, little differentiation in types of nursing care. Nursing education should include courses on the awareness of possible caregiving consequences, such as 1) the caregiver caring for an individual alone and the perception of abandonment, especially for the female caregiver and adult-child caregiver; 2) the caregiver not being able to attend other activities because of caregiving and thus a perception of impact on schedule, especially for the spouse; 3) negative interactions among family members not only between the caregiver and the care-recipient, but other members who the caregiver feels should be offering more assistance adding to perception of abandonment; 4) the possible deterioration in health of the caregiver either mentally (depression) or physically, thus, leading to a perception of impact on health, especially for the female spouse; and 5) deterioration or lack of a family support system leading to more feelings of abandonment.

In many nursing schools, curriculum is technical and hospital based rather than community oriented. Visiting nurse affiliations should be incorporated, particularly including student experiences in home visits to individuals caring for an impaired elderly person in their home. The student needs to follow a family in order to observe and address the caregiver's perception of impact on his/her schedule, his/her health, or on abandonment, or all three dimensions. The students need to be aware that the female caregiver may perceive more abandonment than the male caregiver, or that the female spouse perceives more impact on health than the male spouse, the spouse perceives more impact on schedule than the non-spouse, and that the non-spouse caregiver perceives more abandonment than the spouse caregiver. Another advantage for students being involved in community or visiting nursing is to learn of various community resources or self-help groups in which to refer the caregiver.

In a graduate nursing program, studies on assessment and management of the caregiving situation, and possible consequences of caregiving such as elder abuse should be included. If nurses on the graduate level are aware that the caregiver's perception of impact on schedule, on health, and abandonment can result in the caregiver abusing the elderly person, or the caregiver cannot bear the stress of caregiving, preventive measures can be initiated. The measures mentioned earlier were coordination and referral of respite or in-home health services, support to the caregiver through listening and teaching caregiving skills and promoting self-care so the caregiver's health does not deteriorate. Graduate nursing students should be aware of government programs and policies affecting the caregiver and the elderly recipient. Also, graduate students need to be made aware of how to possibly influence change in government policy such as being active in a professional organization and participating on committees that actively promote change in government policy.

Educational courses should include interviewing and counselling techniques for the graduate nurse, so that he or she can assist the caregiver in coping with crises and anticipatory guidance in regards to the dimensions of impact, such as adult-child caregivers perceive more impact from abandonment than the spouse caregiver. The findings in this research support the fact that the caregivers experience some impact from assisting an impaired person, and nurses of all levels should be aware of the impact, particularly in the dimensions of schedule, health, and abandonment. Supportive counselling can be beneficial in allowing caregiver to express frustration and anger.

### Implications of Nursing Research

The caregiver inventory tool should be utilized in further research in order to strengthen its validity. As has been noted throughout the thesis, various instruments mainly with global ratings have been used to study the impact of caregiving. Findings in this study have been contradictory from other studies. In studies, utilizing the same instrument, comparison of results is more valuable. Through the use of the same instrument, comparison of results increases knowledge.

Through the use of subscales (each dimension of the caregiver inventory) the various dimensions of caregiving can be increasingly understood. By scoring with a global rating as others have done, the score masks each dimension. The item for each dimension (schedule, health, financial, and abandonment) could be researched as a screening instrument for caregivers to determine or predict if particular caregivers are at risk, and to assess if caregivers perceive impact in a particular dimension. If perceived impact is higher in one domain, then assistance can be immediately focused in the area. It can be useful as an assessment tool during an interview of a caregiver by a CNS in primary care. Other dimensions that could be added are a spiritual dimension (what gives life meaning), a dimension of coping, and possibly a dimension involving frustration and resentment.

Other possible ideas for research are as follows:

1. Study if caregivers of an impaired elderly person perceive more strain than other individuals who face unusual and stressful events in their lives.
2. Study caregivers of the impaired elderly in comparison to caregivers of younger impaired adults or impaired children to look at the same dimensions. Are the dimensions perceived with the same amount of impact. If there are differences,

are there reasons that may be beneficial to help relieve impact for the caring of the elderly.

3. Study if caregivers of the impaired elderly perceive more stress or exhibit more physical or mental symptoms than elderly non-caregivers.
4. Compare impact of caregiving among different ethnic groups. For example, do the Amish perceive same impact as Caucasian or black elderly caregivers?
5. Compare perceived impact of caregiving between rural and urban groups.
6. Study interpersonal relationship of caregiver and elderly recipient of care previous to the caregiving situation. Study if relationship has affect on impact from caregiving.
7. Study individual's perspective of caregiving and any positive or negative results (such as guilt, physical mental symptomatology) six months to one year after experience has ended.
8. Study if there is a difference in dimensions between female and male non-spouse caregivers.
9. Research if those providing care to an elderly impaired individual perceive more stress in the caregiving situation than those in other difficult situations.
10. Study reasons some caregivers perceive more impact than others. Are coping and decision making skills better? Is there more support for one caregiver than the other?

## Summary

In Chapter VI, the limitations of the study, the implications for the CNS using Orem's theory, and the implications and recommendations for nursing education and research were presented.

# Appendices

# Appendix A

# Informed Consent Procedure

# APPENDIX A

## Informed Consent Procedure

Before we get started, I would like to take some time to explain what will be involved in taking part in this study and to answer questions you may have about taking part.

Basically, over the course of the year, there will be two home visits which will be arranged at your convenience as well as several telephone calls and mailed questionnaires.

There are some other things that are important for me to let you know about relative to taking part in this study.

One thing is that taking part in the study will not change the health care or services that you are now receiving. The study does not provide any services and cannot arrange for services for you.

Also, if your situation should change during the year so that you are no longer helping your relative, we would still like to maintain contact and ask questions of you.

It is important for you to know that all of your responses during the course of the study are anonymous and confidential. Your name and anything which would identify you personally will be kept separate from the answers you give. Neither your name nor the name of your family member will be given out to anyone else or used in any written reports of the study at any time.

We want you to be aware that taking part in the study is voluntary and you are free to withdraw from the study at any time without consequence.

Do you have any questions about taking part in the study?

I have a written consent form with me that I would like to have you sign. I'll leave one copy of the consent form for you to keep and take one copy to keep with the records of the research study.

IF SUBJECT DOES NOT WISH TO SIGN FORM, LEAVE THEM A COPY AND PROCEED WITH THE INTERVIEW. INCLUDE THIS INFORMATION ON THE INTERVIEWER ASSESSMENT.

# Appendix B

## Consent Form

MICHIGAN STATE UNIVERSITY
Family Caregiver Study

## CONSENT FORM

The study in which we are asking you to participate is designed to learn more about the ways in which caring for an older family member affects the person providing the care.

Over the next year, family caregivers will be interviewed by a member of the Family Caregiver Study research staff three times (at intake, six months, and at one-year). Each interview will take approximately one and one-half hours to complete. Caregivers will be asked to complete written questionnaires and to answer questions asked by the interviewer. They will also be asked to report, each three months during the year, on any health care services used.

If you are willing to participate, please read and sign the following statement:

1. I have freely consented to take part in a study of caregivers and their patients conducted by the College of Nursing and the Department of Family Practice, College of Human Medicine, at Michigan State University.
2. The study has been described and explained to me and I understand what my participation will involve.
3. I understand that participating in this study is voluntary.
4. I understand that I can withdraw from participating at any time.
5. I understand that the results of the study will be treated in strict confidence and, should they be published, my name will remain anonymous. I understand that within these restrictions, results can, upon request, be made available to me.
6. I understand that no immediate benefits will result from taking part in this study, but am aware that my responses may add to the understanding of health care professionals of the experience of being responsible for an older family member.

I, ________________, state that I understand what is required of me as a participant and agree to take part in this study.

Signed ________________________ Date ________________________
(Signature)

MICHIGAN STATE UNIVERSITY

UNIVERSITY COMMITTEE ON RESEARCH INVOLVING
HUMAN SUBJECTS (UCRIHS)
238 ADMINISTRATION BUILDING
(517) 355-2186

EAST LANSING • MICHIGAN • 48824-1046

May 3, 1988

Linda Campbell
28574 Fairlane Drive
Dowagiac, MI 49047

Dear Ms. Campbell:

Subject: "CAREGIVER PERCEPTION OF BURDEN AS RELATED TO SELECTED CAREGIVER CHARACTERISTICS#88-117"

The above project is exempt from full UCRIHS review. I have reviewed this project and approval is granted for conduct of this project.

You are reminded that UCRIHS approval is valid for one calendar year. If you plan to continue this project beyond one year, please make provisions for obtaining appropriate UCRIHS approval prior to May 3, 1989.

Any changes in procedures involving human subjects must be reviewed by the UCRIHS prior to initiation of the change. UCRIHS must also be notified promptly of any problems (unexpected side effects, complaints, etc.) involving human subjects during the course of the work.

Thank you for bringing this project to our attention. If we can be of any future help, please do not hesitate to let us know.

Sincerely,

John K. Hudzik, Ph.D.
Chair, UCRIHS

JKH/sar

cc: B. Given

# Appendix C

# Approval Letter from UCRIHS Review

# Appendix D

## Relevant Questions for Sociodemographic and Other Information for Caregiver

## Appendix D

## SOCIODEMOGRAPHIC - CAREGIVER

I'd like to start today by asking you questions about your background.

1. What is your date of birth: ______/____/______
month/date/year

2. How far did you go in school? Did you complete:

____Grade school or less
____Some high school
____High school
____Some college or technical training
____College
____Graduate or professional school (post baccalaureate degree)

4. INTERVIEWER: MARK SUBJECT'S RACE. CLARIFY IF NECESSARY.

____Caucasian
____Black
____Hispanic
____American Indian
____Oriental/Asian/Pacific Islander
____Other (please specify)__________

3. Sex of Caregiver: ____Male ____Female

6. What is your relationship to the person you provide care for:

____spouse
____parent
____daughter (in-law)/son (in-law)
____brother (in-law)/sister (in-law)
____other (specify__________________________________)

Caregiver Employment

1. Are you currently employed for pay? (CHECK)

____YES Are you employed: ____Full-time
____Part-time

What is your occupation?

______________________________
(write in occupation)

# FINANCES

## FOR SPOUSE CAREGIVERS

"Now I would like to ask you to answer questions about the financial situation of your household. This information will be held in strictest confidence and will not be linked to you as an individual in any way. This information is necessary to describe the financial situations of families in our study as a group."

## FOR NON-SPOUSE CAREGIVER

"Now I would like you to answer questions about your finances and your relatives finances. This information will be held in strictest confidence and will not be linked to you as an individual in any way. This information is necessary to describe the finances of the families in our study as a group. We have separate questions for your finances and for your relatives finances."

## FOR SPOUSE CAREGIVERS

2. Considering all of these sources of income, what was the total income before deducting for taxes for you (and your SPOUSE) in 1986. Was it: (check one)

___$ 0-$1,999
___$2,000-$2,999
___$3,000-$3,999
___$4,000-$4,999
___$5,000-$5,999
___$6,000-$6,999
___$7,000-$7,999
___$ 8,000-$ 8,999
___$ 9,000-$ 9,999
___$10,000-$14,999
___$15,000-$19,999
___$20,000-$24,999
___$25,000-$29,999
___$30,000 or above

## FOR NON-SPOUSE CAREGIVERS

2. Considering all of these sources of income, what was the total income before deducting for taxes for your household in 1986? Was it: (CHECK ONE)

___$ 0-$1,999
___$2,000-$2,999
___$3,000-$3,999
___$4,000-$4,999
___$5,000-$5,999
___$6,000-$6,999
___$7,000-$7,999
___$ 8,000-$ 8,999
___$ 9,000-$ 9,999
___$10,000-$14,999
___$15,000-$19,999
___$20,000-$24,999
___$25,000-$29,999
___$30,000 or above

## RELATIVES FINANCES

2. Considering all of these sources of income, what was your relative's total income before deducting for taxes in 1986? Was it: (CHECK ONE)

___$ 0-$1,999
___$2,000-$2,999
___$3,000-$3,999
___$4,000-$4,999
___$5,000-$5,999
___$6,000-$6,999
___$7,000-$7,999
___$ 8,000-$ 8,999
___$ 9,000-$ 9,999
___$10,000-$14,999
___$15,000-$19,999
___$20,000-$24,999
___$25,000-$29,999
___$30,000 or above

# Appendix E

# Sociodemographic Questions for Relative

## Appendix E

## SOCIODEMOGRAPHIC - RELATIVE

Now, I am going to ask you questions about your relative's background.

1. What is the date of birth of your relative_______/____/___
month/date/year

2. INTERVIEWER: CONFIRM SEX OF RELATIVE IF NECESSARY

Sex of relative: _____ Male
_____ Female

3. INTERVIEWER: CONFIRM RACE IF RELATIVE IS NOT PRESENT -- CLARIFY IF NECESSARY

Race of relative:

_____Caucasian
_____Black
_____Hispanic
_____American Indian
_____Oriental/Asian/Pacific Islander
_____Other (please specify)___________

4. How far in school did your relative go: Did he/she...

____Finish grade school or less
____Complete high school
____Graduate from high school
____Have college or technical training
____Graduate from college
____Complete a graduate or professional degree (post baccalaureate degree)

# Appendix F

## Questions for Relative's Activities of Daily Living

## Instrumental Activities of Daily Living and Mobility

## Appendix F

## CAREGIVER INVOLVEMENT

### I. Questions for Dependencies in Activities of Daily Living

The following pages describe a number of activities that your relative may need help with either some or all of the time. First, for each activity, check YES or NO to indicate whether your relative needs any help with that activity.

1. Does your relative need help with eating?

YES ____ NO ____

2. Does your relative need help with dressing and undressing?

YES ____ NO ____

3. Does your relative need help with combing hair or shaving?

YES ____ NO ____

4. Does your relative need help with taking a shower or bath?

YES ____ NO ____

5. Does your relative need help with using toilet or commode?

YES ____ NO ____

8. Does your relative need help with getting in and out of bed?

YES ____ NO ____

### II. Items for Relatives' Instrumental Activities of Daily Living

10. Does your relative need help with shopping?

YES ____ NO ____

11. Does your relative need help with the housework?

YES ____ NO ____

12. Does your relative need help with laundry?

YES ____ NO ____

13. Does your relative need help with cooking?

YES ____ NO ____

14. Does your relative need help with handling his/her own money?

YES ____ NO ____

15. Does your relative need help with arranging his/her own transportation?

YES ____ NO ____

III. Items for Relative's Mobility

6. Does your relative need help with walking?

YES ____ NO ____

7. Does your relative need help with getting around the house?

YES ____ NO ____

8. Does your relative need help with getting in and out of bed?

YES ____ NO ____

# Appendix G

# Items Utilized from Caregiver Inventory

# Appendix G

## Items Utilized for Each Dimension of Impact (schedule, health, finance, and abandonment)

We are trying to understand how providing care for your family member has affected you, your relationships with others, and your social activities and daily routines.

In the questions that follow, please circle the response that most represents how you feel about each statement. The blank line in some statements represents the name of the elderly person for whom you provide care. It may be helpful for your to place the initials of that person on the blank line. Answer all the questions in response to caring for the elderly person. (Circle one response for each statement.)

EXAMPLE

Since I began caring for _____, my day-to-day schedule has changed a lot.

| STRONGLY AGREE | AGREE | NEITHER AGREE NOR DISAGREE | DISAGREE | STRONGLY DISAGREE |
|---|---|---|---|---|

FINANCIAL IMPACT OF CAREGIVING

3. My financial resources are adequate to pay for things that are required for caregiving.

10. It's difficult to pay for _____'s health needs and services.

16. Caring for _____ has put a financial strain on the family.

31. If I could afford it, I would find some other way to care for _____.

FAMILY ABANDONMENT OF THE CAREGIVERS

2. My family works together at caring for _____.

8. I wish the family depended less on me to care for ___.

15. Since caring for _____, I feel that my family has abandoned me.

22. It is very difficult to get help from my family in taking care of _____.

27. Others have dumped caring for _____ on to me.

41. My family (brothers, sister, children) left me alone to care for _____.

## IMPACT OF CAREGIVING ON SCHEDULE

11. My activities are centered around care for _____.

18. I have to stop in the middle of my work or activities to provide care.

24. I have eliminated things from my schedule since caring for _____.

32. The constant interruptions make it difficult to find time for relaxation.

46. I visit family and friends less since I have been caring for _____.

## IMPACT ON CAREGIVER HEALTH

14. I am healthy enough to care for _____.

29. It takes all my physical strength to care for _____.

36. My health has gotten worse since I've been caring for _____.

50. I have enough physical strength to care for _____.

59. Since caring for _____, it seems like I'm tired all the time.

# Appendix H

# Items for Family/Friends Support

## Appendix H

### Items for Family/Friend Support

13. The questions I have just asked you are about services received through agencies. Now I would like to ask you about assistance you have received for YOURSELF from FAMILY OR FRIENDS.

INTERVIEWER: IF YES, ASK "HOW MANY TIMES IN THE PAST THREE MONTHS..."

IN THE PAST THREE MONTHS, HAVE FAMILY FRIENDS...

a) Checked regularly (two to three times a week) on you to be sure you were all right?
____YES ____NO
How many times: ______

b) Helped you with routine chores (cleaning/washing)?
____YES ____NO
How many times: ______

IN THE PAST THREE MONTHS, HAVE FAMILY OR FRIENDS...

c) Helped you with heavy cleaning or home maintenance or repair?
_____YES _____NO
How many times: _____

d) Helped you with legal or money matters:
_____YES _____NO
How many times: _____

e) Helped you with transportation for yourself?
______YES _____NO
How many times: _____

f) Taken care of your relative so you could have time away?
_____YES ____NO
How many times: ____

g) Made meals for you?
_____YES _____NO
How many times: _____

3. I'd like to know who helps with your relative's care. Please include friends, relatives and people you pay to provide care for your relative.

RELATIONSHIP OF PERSON TO PATIENT

a. ________________
b. ________________
c. ________________
d. ________________
e. ________________

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