ABSTRACT

SELF-CARE AND THE RELATIONSHIP OF SELECTED VARIABLES TO SELF-CARE: AMONG PRIMARY CAREGIVERS TO ALZHEIMER'S DISEASE PATIENTS

By

Kathleen A. Powers-LaMoe, R.N., C-F.N.P.

The purpose of this retrospective and descriptive study was to describe Alzheimer's caregivers' self-care and determine the relationship of independent variables (caregiver: age, sex, education, employment, relation to Alzheimer's patient, duration of caregiving, health, perceived health, depression, social interaction, amount of assistance from family/friends and impact of caregiving on schedule) with dependent variables representing caregiver self-care (time-care, physical-care, social-care, sleep-care, diet-care). Data utilized were collected among 120 primary caregivers of Alzheimer's patients via caregiver interviews and administered questionnaires.

Data were analyzed (secondary analysis) using descriptive statistics and hierarchical multiple regression analyses. The significant findings were a positive relationship between: dependent variable 'physical-care' and independent variable 'caregiver health'; dependent variable 'time-care' and independent variable 'caregiver depression'; dependent variable 'sleep-care' and independent variables 'caregiver depression' and 'caregiver health'; dependent variable 'social-care' and independent variable 'caregiver depression'. The dependent variable 'diet-care' was not related to any independent variables in the study.

ACKNOWLEDGEMENTS

Sincere thanks and appreciation are extended to Barbara Given, R.N., Ph.D. and Charles W. Given, Ph.D. for the use of their data that made this study possible. Without their help this study would not have been possible.

I would also like to thank the other members of my committee, Sharon King, R.N., Ph.D., Patty Peek, R.N., MSN and Linda Spence, R.N., MSN, for their feedback and encouragement throughout the study. I especially appreciate the support and responsiveness they demonstrated during the 'long-distance' phase of completing this project.

A special note of gratitude is extended to Manfred Stommel, Ph.D., who spent many hours assisting me with computerized data analysis. There is no doubt this study would not have been completed without him.

Finally, I owe the greatest debt of thanks and appreciation to my family and friends for standing by me throughout the process of completing this study. To my husband Jeff, thank-you for being understanding, supportive, and most of all, patient.

TABLE OF CONTENTS

CHAPTER

Concepts:

CHAPTER

APPENDICES

LIST OF TABLES

TABLE

LIST OF FIGURES

FIGURE

CHAPTER 1

The Problem

Introduction and Background

Alzheimer's Disease is a progressive, irreversible, neurological disorder affecting an estimated 2.5 million American adults (Alzheimer's Disease and Related Disorders Association, ADRDA, 1987). The disease, first described by German neurologist Alois Alzheimer in 1906, is currently the most common form of dementing illness (ADRDA, 1987). With an insidious onset, Alzheimer's Disease progresses gradually toward death. Average duration of the disease is five to ten years, however this varies considerably for each person (Gwyther and Matteson, 1983). With an annual mortality rate of 100,000 lives, Alzheimer's Disease is the fourth leading cause of death in adults, following heart disease, cancer, and stroke (ADRDA, 1987). No definitive cause or cure for Alzheimer's Disease is yet known. Diagnosis can only be confirmed via post mortem examination of brain tissue for the classic Alzheimer pathology of neurofibrillary tangles, neuritic plaques and granulovacular changes (United States Department of Health and Human Services, 1987). Most victims are over 65 years old, however, Alzheimer's Disease can strike in the fourth and fifth decades of life (ADRDA, 1987). There is currently debate as to whether Alzheimer's occurring before age 65 differs significantly from the same disease occurring after age 65 (Lampe, 1987). Some studies (Bird, Stranaham, Sumi, Raskind, 1983; Bondareff, 1983) have reported Alzheimer's disease occurring in a younger person is more severe and involves more extensive biochemical abnormalities. The debate is unresolved.

An aspect of Alzheimer's disease not in question is its manifestation in America's increasing elderly population. The incidence of Alzheimer's Disease increases from 5% for those over 65 years of age, to 20% for those over 80 years (Kahan, Kemp, Staples, Brummel-Smith, 1985). With the "graying" of America, the over 65 population (29 million) will increase to 35 million in the year 2000 and to 51 million in the year 2020 (Staff, 1987). Understandably, the National Institute on Aging (NIA) has made Alzheimer's Disease a priority issue and estimates that 3.8 million people will be affected with the disease by the year 2000, and 8.8 million by 2050 (Staff, 1987). These statistics clearly validate Alzheimer's Disease as a major concern of caregivers, clinicians, and policy makers, whose task is managing the disease both present and future.

Symptoms of Alzheimer's Disease include, "a gradual memory loss, decline in ability to perform routine tasks, impairment of judgement, disorientation, personality change, difficulty in learning, and loss of language skills" (ADRDA, 1987, p.1). The rate of deterioration varies for each person however, the disease eventually renders all victims totally incapable of caring for themselves. It is this eventual outcome of total dependency which produces the so called "two victims" of Alzheimer's Disease -- the patient and the caregiver (O'Connor, 1987).

The caregiving aspect of Alzheimer's accounts for a significant portion of the economic impact of the disease.

"Approximately 60% of all nursing home patients are affected with Alzheimer's or a related disorder. Average cost for nursing home care is $25,000 per year" (Staff, 1987. p.15). Be that as it may, the nursing home population of Alzheimer's patients remains small in comparison to Alzheimer patients cared for in the home. "Of the 2.5 million Americans with Alzheimer's, 1.5 million are cared for in the home . . . with an average annual cost to the family of $18,000" (Staff, 1987, p.15). In sum, the national cost of Alzheimer's is estimated to be $40 billion per year, accounting for physician costs, nursing home charges, and lost wages of caregivers and patients alike (Staff, 1987).

In the literature of the past five years, the finding that family members make-up the major component of the long-term care delivery system for impaired older adults, has evolved from insight to accepted fact (Cantor, 1983; Clark and Rakowski, 1983; Deimling and Bass, 1986; Fenger and Goodrich, 1979; Gilhooly, 1984; Goldman and Luchins, 1984; Goldstein, Regnery, Wellin, 1981; Haley, 1983; Johnson and Catalano, 1983; Montgomery, Gonyea, Hooyman, 1985; Sheldon, 1982; Soldo and Myllyluoma, 1983; Zarit, Reever, Bach-Peterson, 1980). Faced with a growing need for long-term care services at a time when public resources are shrinking, the family is increasingly called upon to fill the primary caregiver role for dependent older adults (Montgomery et al. 1985).

Support from individual family members or others is commonly referred to, in the literature, under the rubric of "family caregiving" (Johnson and Catalano, 1983). "Family caregiving" is a misnomer for a phenomena defined by Shanas (1979) as the principal of substitution. The principal of substitution involves individuals providing care in serial order rather than as a shared functioning unit (Johnson and Catalano, 1983). The most common serial order of primary caregivers places the spouse as the first primary caregiver, followed by a child, and in the absence of offspring, another individual is designated as the primary caregiver (Johnson, 1983).

The number of research reports and articles on individuals assuming major responsibility for a person with Alzheimer's Disease is expanding (Barnes, Raskind, Scott, Murphy, 1981; Caserta, Lund, Wright, Redburn, 1987; Chenoweth and Spencer, 1986; Colerick and George, 1986; Gwyther and Matteson, 1983; Kahan et al. 1985; Pratt, Wright, Schmall, 1987; Pratt, Schmall, Wright, Cleland, 1985; Scott, Roberto, Hutton, 1986; Williams-Schroeder, 1984; Winogrond, Fisk, Kirsling, Keyes, 1987; Zarit and Zarit, 1982). The works of the aforementioned authors support the observation that individuals caring for a person with Alzheimer's Disease are at risk for a variety of negative effects. These negative effects are referred to in the literature under the general term of, caregiver burden (Poulshoch and Deimling, 1984). George and Gwyther (1986) define caregiver burden as, "the physical, psychological or emotional, social, and financial problems that can be experienced by family members caring for impaired older adults" (p. 253).

The converse of caregiver burden, is the notion of caregiver well-being. Dimensions of caregiver well-being found in the literature include: caregiver health, caregiver mental health, caregiver participation in social and recreational activities, caregiver use or non-use of psychotropic drugs, and caregiver financial resources/economic status (Colerick and George, 1986; George and Gwyther, 1986; Pratt et al. 1987). As noted by George and Gwyther (1984), "it appears that caregiver burden and caregiver well-being are but opposite sides of the same coin" (p.2). Nevertheless, the investigation of caregiver well-being has resulted in documentation that Alzheimer caregivers often shoulder the burden of caregiving beyond healthful limits (Barnes et al. 1981; Cantor, 1983; Chenoweth and Spencer, 1986; Colerick and George, 1986; George and Gwyther, 1986; Goldstein et al. 1981; Gwyther and Matteson, 1983; Pratt et al. 1987; Scott et al. 1986).

Alzheimer caregivers are observed to disregard their own well-being in order to continue their availability to the Alzheimer victim (Gwyther and Matteson, 1983). This action on the part of Alzheimer caregivers appears paradoxical, as the caregivers own well-being will ultimately impact the caregivers ability to execute the caregiving role. It is this paradox, which created the premise to explore an area largely unreported on in the caregiver literature to date, this is the self-care practices of caregivers of Alzheimer patients.

The rational for investigating the self-care practices of Alzheimer caregivers is three-fold. First, current literature is devoid of a description of Alzheimer caregivers' self-care practices. Second, variables need to be identified which inhibit or promote the Alzheimer caregivers' level of self-care. The contention here being that, the more caregivers attend to their own self-care, the longer they will remain viable in the caregiving role. Health professionals are concerned about the caregivers capability to provide long-term care. Third, methods are needed to monitor and assist the caregiver in maintaining or achieving adequate care of themselves.

Alzheimer caregivers need assistance with self-care because the reported general attitude of caregivers is: "whatever the physical, psychological, and other costs of caretaking, they are the price one pays to avoid or defer institutionalizing the patient" (Goldstein et al. 1981, p. 27). Despite the hardships, caregivers appear to be strongly and genuinely motivated by a desire to keep the patient at home (Goldstein et al. 1981).

It is obvious that humans spend a large portion of their lives caring for themselves. While public interest in self-care has grown within the past decade, nurses have long recognized the importance of clients achieving competence in their own self-care. Orem's (1985) self-care deficit theory of nursing, provides a framework for nursing as a practice discipline. Within Orem's framework, self-care is designated as a universal requirement for health maintenance and continued life (Orem, 1985). Furthermore, Orem (1985) states that, "nursing is made legitimate by humans' continuous need for self-maintenance and self-regulation" (p. 107). Orem's self-care deficit theory of nursing is utilized in this study as a guiding conceptual framework for examining the relationship of the concepts: caregiving, self-care, and nursing. The concepts: caregiving, self-care, and nursing, are analyzed within the context of caregiving; in the Alzheimer's Disease setting.

To further describe and explain the phenomenon of self-care, a second theoretical model, Pender's (1987) health promotion model, is also incorporated into the conceptual framework of this study. Pender's model is used to look specifically at the caregiver and factors which may modify the level of self-care, or health promotive activities the caregiver performs.

The frameworks of Orem (1985) and Pender (1987), are used to produce a theory based investigation of Alzheimer caregivers self-care, and determine what affect selected variables have in moderating the level of caregiver self-care. Data from this study will be used to discuss how nursing systems in primary care may be utilized to positively impact Alzheimer caregivers self-care.

Purpose of the Study

The purpose of the study is twofold. The first study purpose is to describe the self-care practices of a group of primary caregivers to Alzheimer patients. The second purpose of the study, is to determine what relationship selected independent variables share with the dependent variable of caregiver self-care.

The results of this study can be used to document the self-care practices of a group of primary caregivers to Alzheimer patients. The research can also provide empirical evidence of how selected study variables affect the caregivers' level of self-care. As a result of the framework developed for this study, modified versions of Orem (1985) and Pender's (1987) models will gain support as theoretical frameworks used to analyze self-care and health promotion respectively. Research of Alzheimer caregivers self-care and variables which impact the caregivers self-care practices is necessary to develop strategies to improve or maintain caregivers level of self-care.

Problem Statement

The specific questions are:

1. What are the reported self-care practices of a group of primary caregivers to Alzheimer patients?

2. What relationship do selected variables have with the caregivers' performance of self-care? Specifically: How are the following independent variables associated with the Alzheimer caregiver's self-care?

Caregiver age.
Caregiver sex.
Caregiver marital status.
Duration of caregiving.
Caregiver education.
Caregiver employment status.
Caregiver relation to Alzheimer patient.
Caregiver health.
Caregiver perceived health (self-perception).
Caregiver depression.
Social interaction of caregiver.
Amount of assistance caregiver receives from family and friends.
Impact of caregiving on caregiver schedule.

Research is needed to answer these questions. The data can be used to answer questions concerning the correlation of caregiver: demographics, health, depression, perceived health, schedule, assistance from family and friends and social interaction, with the dependent variable -- caregiver self-care. Data from previous studies documents the negative impact caregiving has on the caregiver's health status (George and Gwyther, 1986; Haley, 1986; Pratt et al. 1985; Pratt et al. 1987). Data from this research study is presented to document the effect caregiving has on the caregiver's self-care practices.

Knowledge of caregiver self-care practices is essential to clinicians, who recognize self-care as a determinant of quality of life and longevity. The data from this study can be used to provide information to improve understanding of caregiver self-care practices and the impact selected variables have on caregiver self-care. The need to investigate the self-care behavior of caregivers is supported by the fact that self-care constitutes 75% of all health care in the United States (Pender, 1987). Therefore, to address the self-care competence of a caregiver is to address a significant portion of the caregiver's health needs. Professional nurses can also benefit from the study results, as a contribution to the development of strategies to treat, "self-care deficit" an accepted nursing diagnosis (Gordon, 1982).

Information on caregiver self-care is a first-step in investigating self-care as a means of promoting caregiver viability and health. Exploring the impact of selected variables on caregiver self-care aids in identification of high risk caregivers (i. e. those caregivers at risk for low self-care). Futhermore, understanding how selected variables affect caregiver self-care will provide answers as to how caregiver self-care is helped or hindered. Providing support to the Alzheimer caregiver is a timely goal. This research study is a contribution toward reaching that goal.

The data utilized in the study to answer the research questions were collected as part of a federally funded research project, The Impact of Alzheimer's Disease on Family Caregivers (ZR01MH41766, 1986) C.W. Given and C. Collins, co-principal investigators.

Definition of Variables

The independent variables in this study are the caregivers': age, sex, marital status, duration of caregiving, education, employment status, relation to Alzheimer patient, health, perceived health status, depression, social interaction, amount of assistance from family and friends, and, schedule (impact of caregiving on caregiver's schedule). The single dependent variable is caregiver self-care.

Caregiver

In this study, caregiver is defined as, "a person who identifies themself as the primary person responsible for the care of the Alzheimer patient in their charge" (Given and Collins, 1986, p. 68). To be defined as a caregiver in this study, the individual must also be: residing with the Alzheimer patient, and related to the Alzheimer patient (Given and Collins, 1986). Furthermore, caregivers must also be able to read and write, not blind, and ambulatory, with no acute or unstable medical conditions (Given and Collins, 1986). The reason for the caregiver criteria listed above is explained as the other study variables are defined.

Demographic Variables

The independent variables in the study are further broken down into demographic variables and non-demographic variables. The demographic variables of the study are caregiver: age, sex, marital status, education, employment status, relation to Alzheimer patient, and duration of caregiving.

Caregiver Age

Caregiver age is defined as the length of time a caregiver has lived, as measured in chronological years. No age qualifications were required to participate in this study, caregivers of any age were permitted as subjects. Including caregivers of all ages is a "mixed blessing". Using caregivers of various ages increases the effect of sample variation in study measurements. Furthermore, younger caregivers may be involved in a "dual" caregiving role of caring for their young children and elderly parents at the same time. Younger caregivers are likely to experience stressors unique to their situation, and different from the experiences of older caregivers. The lack of sample homogeneity in regard to caregiver age will be addressed later in Chapter VI.

Caregiver Sex

Caregiver sex is defined as the caregiver's gender, male or female. The importance of caregiver sex as a study variable is highlighted by Cantor (1983). "The homogenization of such crucial variables as type of relationship, sex, age, health and work status of caregivers, has resulted in obscuring the differences among various groups of caregivers and the types of stress each may be experiencing in the process of giving assistance" (p. 597).

As a demographic variable, sex has been clearly shown to be correlated with use of health care services (more frequent use by females). In regard to the use of preventive services in the absence of symptoms, sex is the demographic variable most predictive of preventive behaviors and women exhibit a predisposition to engage in preventive behaviors more frequently than men (Pender, 1987).

While the vast majority of caregivers are female, male caregivers are becoming more prevalent, especially in Alzheimer cases where a male spouse may be required to fill the caregiving role for his affected wife (Cantor, 1983). For a male, caregiving duties may represent a reversal of long-established roles and life patterns, increasing the potential for stress in a male caregiver (Cantor, 1983). For the purpose of this study, caregiver sex is included to examine caregiver self-care practices in relation to caregiver gender.

Caregiver Marital Status

Marital status of the caregiver is defined as the caregiver's current conjugal affiliation. Cantor (1983) reports that, "In many ways spouses appear to be the high risk group among caregivers. Their household incomes are the lowest of all caregivers, and as one would expect, they are more likely to be old themselves" (p. 599). In regard to caregiver strain or burden, Cantor (1983) notes the most important variable by far is the type of caregiver and his or her relationship to the care-receiver. "The closer the bond, the greater the amount of strain, placing spouses at highest risk" (Cantor, 1983, p. 601). For the purpose of this study, caregiver marital status is evaluated as a variable which may affect the caregiver's self-care behavior.

Duration of Caregiving

Duration of caregiving is defined as the length of time (as measured in years and/or months) the person designated as the primary caregiver, has provided or coordinated the resources required by the Alzheimer patient (Zarit et al. 1980). While there is currently a paucity of longitudinal studies of caregiving, one study by Gilhooly (1984) found unexpected correlations between duration of caregiving and caregiver morale and mental health. "The longer the supporter had been giving care, the higher his or her morale and the better their mental health" (Gilhooly, 1984, p. 40). For the purpose of this study, duration of caregiving is assessed as a possible variable impacting a caregiver's level of self-care.

Caregiver Education

Caregiver education is defined as the highest level of formal study or training the caregiver has achieved. Caregiver education is commonly used as a demographic variable and appears in several research studies (Colerick and George, 1986; Cantor, 1983; Johnson and Catalano, 1983; Pratt et al. 1985; Zarit et al. 1980). Caregiver education is frequently collected as part of the demographics, yet there is little mention of caregiver education in the results sections of the aforementioned studies. To understand its affect as a study variable, caregiver education must be explored beyond a frequency measure. For the purpose of this study, the correlation of caregiver education to caregiver self-care is explored.

Caregiver Employment Status

Employment status of the caregiver is defined as the caregiver's current status of being either employed or unemployed. Caregiver employment emerged as a predictor of institutionalization among Alzheimer caregivers in a study by Colerick and George (1986). It must be noted however, that the employed caregivers in Colerick and George (1986) were employed daughters who reported high stress due to their conflicting commitments as an employee and a caregiver. Due to the age criteria for this study, many of the caregivers are likely to be retired. Nevertheless, the effect of caregiver employment status on caregiver self-care is unknown and will be evaluated in this study.

Caregiver Relation to Alzheimer Patient

Caregiver relation to the Alzheimer patient is defined as the familial or social relationship the caregiver and Alzheimer patient share. The nature of the patient-caregiver bond is reported as an important factor in: caregiver morale and mental health, (Gilhooly, 1984) probability of institutional placement of the patient, (Colerick and George, 1986) and caregiver ability to get along well with the patient (Cantor, 1983). In addition, Poulshock and Deimling (1984) report spouse caregivers have more obvious signs of decreased well-being on objective measures, but report less subjective strain than adult child caregivers. The impact of caregiver/patient relation on caregiver self-care is investigated in this study.

Non-Demographic Variables

The non-demographic, independent variables include caregiver: health, perceived health status, depression, social interaction, amount of assistance from family and friends, and the impact of caregiving on the caregiver's schedule. The definitions of these variables follow.

Caregiver Health

Efforts to define health as a human phenomenon are constantly evolving and at any point in time many definitions exist (Dunn, 1980; Hoyman, 1975; Orem, 1985; Patrick, Bush, Chen, 1973; Wylie, 1970). One of the most frequently cited definitions of human health is the 1974, World Health Organization (WHO) definition, "Health is a state of complete physical mental, and social well-being and not merely the absence of disease and infirmity" (Murray, Nolan, Leonard, Zentner, 1979, p.5). The WHO (1974) definition of health has been criticized as being an ideal rather than a realistic goal for human health (Pender, 1987).

The nurse theorist, Orem, offers a definition of health; "Health is a term used to describe living things when they are structurally and functionally whole or sound" (Orem, 1985. p. 173).

Pender does not define health, but proposes that the state of the art in defining health lies in the answers to five questions.

> 1. Is health a separate and distinct concept from illness or is illness subsumed within the broad concept of health?
> 2. Does health represent a state to be attained or an ongoing dynamic process throughout the life cycle?
> 3. Are health and wellness the same or different constructs?
> 4. Is the definition of health universal or culturally specific?
> 5. Is health a multilevel concept applicable to individuals, families, communities, and societies?
>
> (Pender, 1987, p. 16)

In this study, health refers to the illness level of the caregiver. Here, health of the caregiver is defined as the number of chronic diseases or physical problems the caregiver experiences, and the degree to which these diseases or problems negatively impact the caregiver's life-style. This is not a purely objective measure of caregiver health, yet, for the purpose of this study, the variable caregiver health, is designated as an objective assessment of the caregiver's health.

Caregiver Perceived Health Status

Perceived health status is defined as the rating or condition a person selects to describe his/her current physical health. Therefore, perceived health status is a person's subjective evaluation of his/her own state of health. Haley (1986) comments on the use of perceived health as a study variable; "The standard single-item scale (1=excellent 2=good 3=fair 4=poor) used in many studies to assess a person's perceived health status, has been shown to correlate highly with physician ratings of health, and to be a better predictor of subsequent mortality than objective health ratings" (p. 13). In this study, the caregiver's perceived health status is defined as a subjective measure and is collected in the manner described by Haley (1986).

Caregiver Depression

Various definitions of depression exist, due to the various degrees and contexts in which the phenomenon of depression occurs. Burgess and Lazare (1976) outline four definitional categories of depression.

> 1. Depression as a mood state.
> 2. Depression as a syndrome or symptom complex.
> 3. Depression as a disease process or diagnostic category.
> 4. Depression as a complex of psychodynamic mechanisms. (p. 213)

Within each of the categories above are terms used to define the depression more specifically. When depression is described as a mood state, it is important to differentiate the mood of sadness from the mood of depression (Burgess and Lazare, 1976). A dichotomy with considerable clinical value in defining depression as a syndrome or symptom complex, is the reactive or endogenous distinction. Briefly, reactive depression is based on a precipitating event, whereas in endogenous depression the precipitant is not evident (Burgess and Lazare, 1976). Depression as a disease process or diagnostic category often includes distinctions between unipolar and bipolar depression (Burgess and Lazare, 1976). Unipolar depression lacks a cycle of mania, whereas bipolar depression refers to recurrent manic attacks with or without depressive episodes (Burgess and

Lazare, 1976). The definition of depression as a complex of psychodynamic mechanisms, is based on psychodynamic theories developed to explain the phenomenon of depression. For the purpose of this study, caregiver depression is defined in the psychodynamic theory mode as, "An ego state in which the individual's emotional expression of helplessness and powerlessness occurs. The depression, as an ego state, is characterized by loss of self-esteen in reaction to three dynamic issues: 1) the wish to be worthy, loved and appreciated; 2) the wish to be good, loving, and unaggressive; 3) the wish to be strong, superior, and secure" (Burgess and Lazare, 1976, p. 220).

A limited amount of research is available at this time on caregiver depression (Haley, 1986; Pagel, Becker, Coppel, 1985). A review of available articles and research pertinent to caregiver depression is provided in Chapter Three of this study.

Caregiver Social Interaction

The social interaction of the caregiver is defined as the quantity and types of contacts caregivers have with others in their environment (Given and Collins, 1987). As a study variable, caregiver social interaction is defined as a measure of how socially connected or isolated the caregiver is.

The importance of caregiver social interaction is documented through the research of Zarit et al. (1980). In their study, the extent of burden reported by primary caregivers was not related to the severity of the patient's Alzheimer disease, but was associated with the number of visitors to the household (Zarit et al. 1980). No information was elicited on what visitors were doing or the quality of the visits. Nevertheless, the sheer quantity of visits from other people was important to relieving the caregiver's sense of burden (Zarit et al. 1980). For the purpose of this study, caregiver social interaction is evaluated for any correlation with the dependent variable, caregiver self-care.

Caregiver Amount of Assistance From Family and Friends

Caregiver amount of assistance from family and friends is defined as the assistance family and friends provide in performing tasks for the caregiver (Given and Collins, 1987). In this study, the tasks family and friends may assist with include: routine chores, heavy cleaning, transportation, making meals, watching the Alzheimer patient so the caregiver may have time away, and, legal or money matters (Given and Collins, 1987). For the purpose of this study, assistance from family and friends is labeled as behavioral support and may be thought of as a dimension of social support for the caregiver. Research on the absence or presence of assistance for the primary caregiver, supports the finding that the higher the level of practical or behavioral support, the lower the caregiver's perceived sense of burden (Goldstein et al. 1981; Montgomery et al. 1985; Scott et al. 1986; Scott et al. 1987; Zarit and Zarit, 1982). In this study, the amount of assistance provided to the caregiver by family and friends is evaluated for any correlation with the dependent variable, caregiver self-care.

A brief comment on the two previous variables, caregiver social interaction and caregiver amount of assistance from family and friends. When combined, these variables yield a definition befitting the construct -- social support. As Dimond and Jones (1983) note in their conceptual analysis of social support: "diverse definitions of social support abound, yet these definitions converge on several points" (p. 238). Hubbard, Muhlenkamp and Brown (1984) offer the idea of social support as a multifaceted construct comprised of, "the communication of positive affect, a sense of belonging or social integration and elements of reciprocity" (p. 266).

Researchers have begun to explore the relationship between what people do to promote healthy life-styles, and how they perceive their level of social support (Hubbard et al. 1984). This relationship between self-care and social support has not been investigated among Alzheimer caregivers. The current study will determine what impact the variables, caregiver social interaction and caregiver amount of assistance from family and friends have on Alzheimer caregivers' self-care practices.

Impact of Caregiving on Caregiver's Schedule

The impact of caregiving on the caregiver's schedule is defined as the degree to which caregiving alters the caregiver's normal daily schedule (Given and Collins, 1987). Due to the added demands of caregiving, the amount of time available to the caregiver for personal needs or routines may change. In an effort to identify factors related to caregiver objective burden, Montgomery et al. (1985) reports, "tasks that confine the caregiver in terms of time schedules and/or geographic location, were found to best predict objective burden" (p.24-25). Many caregivers report that being awakened by the patient at night is the most disruptive occurrence in their normal schedule (Goldstein et al. 1981). It seems logical that interruptions in the caregivers' normal schedule and/or free time may effect the caregivers' self-care practices. This study will determine what impact caregiving has on the caregivers' schedule and how this in turn impacts the self-care practices of the caregiver.

Caregiver Selfcare

As the single dependent variable in the investigation, caregiver self-care is the outcome variable of interest. Selfcare practices are defined by Steiger and Lipson (1985) as, "activities initiated or performed by an individual, family or community to achieve, maintain or promote maximum health" (p. 12). Pender (1987) defines self-care as, "actions directed toward minimizing threats to personal health, self-nurturance, self-improvement, and personal growth" (p. 185). Orem (1985) offers a definition of self-care as, "the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health and well-being" (p. 84).

For the purpose of this study, caregiver self-care is defined as generic (not gender specific) activities, performed by caregivers in the areas of: nutrition, disease prevention, exercise, and stress reduction/relaxation, to improve or maintain good health. The link between health practices and health has been well documented, (United States Department of Health, Education, and Welfare, 1979) and few would dispute the fact that a person's life-style has a significant impact on the individual's health. Studies have been done to examine the impact caregiving has on the caregiver's physical and/or mental health (Deimling and Bass, 1986; George and Gwyther, 1986; Haley, 1986; Gilhooly, 1984; Poulshock and Deimling, 1984; Pratt et al. 1987). What is unknown, and the focus of this research, is what relationship caregiving has with the caregiver's self-care practices and/or behaviors.

Assumptions

The following assumptions are made in this research:

1. The concepts outlined in the conceptual framework and defined in Chapter Two of this study, are real and measurable phenomena.

2. Measuring the impact of the identified independent variables is a reliable method of measuring the effect of caregiving on the dependent variable caregiver self-care.

3. Caregiver self-care behaviors can impact and/or improve the caregivers health status and viability in the caregiver role.

Limitations

This research has the following limitations:

1. Subjects who agreed to participate in this study had to meet specific criteria to be selected. Therefore, it is probable that the findings are not representative of all primary caregivers of Alzheimer patients.

2. The points in time at which data were collected may not be representative of the usual perceptions and behaviors of the study participants. Other points in time may be more representative.

3. The study is cross-sectional, and a convenience sample is utilized. Another study design (i. e. longitudinal), and another method of sampling (i. e. random), may be more appropriate, and enhance the generalizability of results.

4. The need to express a socially desirable response may have affected the responses of participants.

5. All possible factors affecting caregiver self-care practices are not addressed in this study. Findings may be due, in actuality, to an interrelationship of factors other than the ones identified in the study. Examples of such factors which are not included in this study are: the caregivers' self-efficacy, caregivers' perceived benefits or barriers to self-care practices, and caregivers' perceived control of their own health.

Overview of Chapters

Presentation of this study is organized into six chapters. Included in Chapter One is the introduction, the purpose of the research, the problem statement and research questions, the background of the problem, definitions of the study variables, and the assumptions and limitations of the study. In Chapter Two, the concepts and relevant theory are integrated into a conceptual framework that is the basis for the study. A review of the literature is presented in Chapter Three, linking this research with the work and ideas of others concerned with the health and well-being of caregivers. A presentation of the methods of research used to conduct the study is found in Chapter Four. Included are the sampling procedure, research design, instrumentation, and procedures for informed consent and human rights protection. Data and analyses are presented in Chapter Five. A summary and discussion of findings, implications for nursing and primary care, and recommendation for future research are presented in Chapter Six.

CHAPTER II

Conceptual Framework

Overview

This chapter includes a discussion of the research problem through explication of the theoretical concepts which form the conceptual framework of the study. Organized into sections, the chapter begins with a brief discussion of Orem's (1985) theory of self-care and Pender's (1987) health promotion model. The aforementioned theory and model are presented first, to show the origins of the conceptual framework developed for this investigation. Next, a description of the relationship between the study variables and the theoretical concepts is presented. Lastly. Orem's (1985) theory of nursing systems is utilized to support the link between this research and nursing theory/practice.

To reiterate, the purpose of the study is to examine the relationship of caregiver: age, sex, marital status, duration of caregiving, employment status, relation to Alzheimer patient, health status, perceived health status, depression, social interaction, assistance from family and friends, and schedule interruptions due to caregiving, within a conceptual framework to determine what effect these variables have on caregiver self-care behavior.

Orem's Theory of Self-Care

Orem refers to her self-care deficit theory of nursing as a general theory of nursing (Orem, 1985). This general theory of nursing is constituted by Orem (1985), from three related theoretical constructs;

> 1. The theory of self-care deficits.
> 2. The theory of self-care.
> 3. The theory of nursing systems.
>
> (p. 33)

In sum, Orem (1985) proposes three separate but articulated theoretical constructs within the (general) self-care deficit theory of nursing. For the purpose of this study, only two of the three theoretical constructs proposed in Orem's (1985) self-care deficit theory of nursing are utilized (i. e. the theory of self-care and the theory of nursing systems). A modified version of Orem's (1985) theory of self-care is incorporated into the conceptual framework of this research. Later in this chapter, Orem's (1985) theory of nursing systems is used to support the link between this research and nursing theory/practice.

To illustrate Orem's theory of self-care, a model is presented in Figure 1. The theoretical construct self-care, is based on Orem's (1985) proposition that, "self-care and dependent care are systematized, deliberate actions that, when continuously and effectively engaged in, regulate structural integrity, human functioning, and human development, as necessary for the continuance of life" (Orem, 1985, p.85). The model in Figure 1, combines two models from Orem (1985, p. 85) to

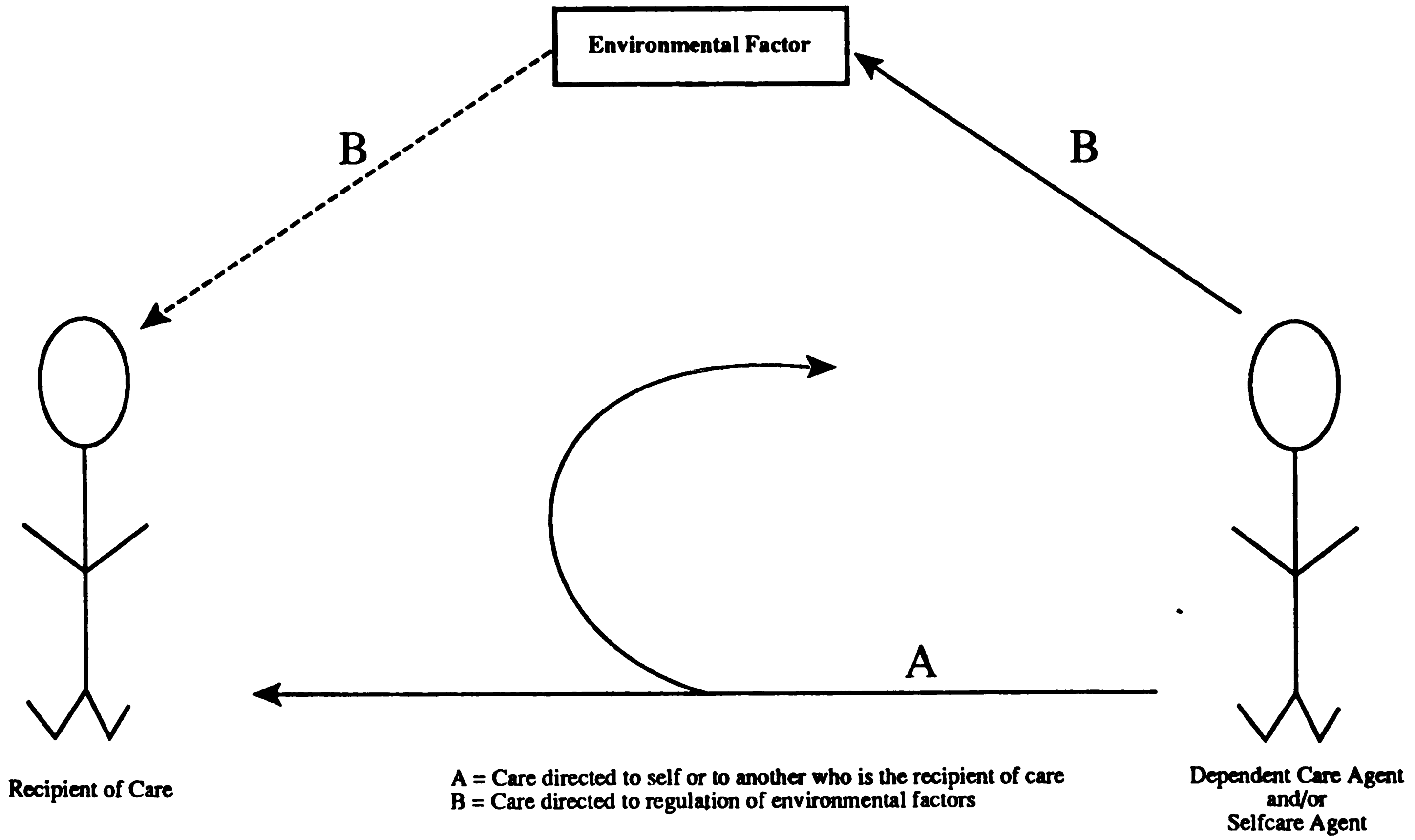


Figure 1. Orem, 1985, p. 85

illustrate the theory of self-care. In the model, the figure on the right is named self-care agent, when self-care is 'for oneself' as represented by the curved arrow labeled 'A' directed back toward the self-care agent. The figure on the right is named dependent care agent, when self-care is 'given by oneself' to another, as represented by the straight portion of arrow 'A' directed to the recipient of care on the left. The environmental factor and solid arrow labeled 'B' represent care directed to the regulation of environmental factors by the dependent or self-care agent (Orem, 1985). Regulated or unregulated environmental factors also impact the recipient of care and this is modeled by the perforated arrow labeled 'B'.

The theory of self-care is applicable to Alzheimer's Disease as Orem (1985) notes, "The aged person requires total care or assistance, whenever declining physical and mental abilities limit the selection or performance of self-care actions" (p. 84). Orem (1985) explains self-care as a practical response to an experienced demand to attend to oneself or a dependent other. Caregivers appear to disregard their own self-care demand, in an effort to maintain the self-care demand of a dependent other. Research supports the finding that some caregivers experience a decrease in health status as a result of caregiving demands (Barnes et al. 1981; George and Gwyther, 1986; Haley, 1986; Pratt et al. 1987).

As defined by Orem (1985), "self-care is the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health, and well-being" (p. 84).

According to Orem (1985), self-care has purpose and the outcomes to be achieved through self-care are termed, self-care requisites. Three types of self-care requisites are identified by Orem (1985): universal, developmental and health deviation. In this study, universal self-care is the self-care requisite of interest, and is described as:

> . . . common to all human beings during all stages of the life cycle, adjusted to age, developmental state, environment and other factors. Universal self-care is associated with life processes, with the maintenance of the integrity of human structure and functioning, and with general well-being.
>
> (Orem, 1985, p. 90)

Effectively meeting the universal self-care requisites of each person, is part of the goal in the primary prevention of disease and ill health (Orem, 1985). Eight universal self-care requisites are outlined by Orem (1985):

> 1. The maintenance of a sufficient intake of air.
> 2. The maintenance of a sufficient intake of water.
> 3. The maintenance of a sufficient intake of food.
> 4. The provision of care associated with elimination processes and excrements.
> 5. The maintenance of a balance between activity and rest.
> 6. The maintenance of a balance between solitude and social interaction.
> 7. The prevention of hazards to human life, human functioning, and human well-being.
> 8. The promotion of human functioning and development within social groups in accord with human potential, known human limitations, and the human desire to be normal. Normalcy is used in the sense of that which is in accord with the genetic and constitutional characteristics and the talents of individuals. (p. 90-91)

Self-care practices performed to fulfill the universal self-care requisite, are judged therapeutic to the degree that they contribute to the following results.

> 1. Support of life processes and promotion of normal functioning.
> 2. Maintenance of normal growth, development and maturation.
> 3. Prevention, control or cure of disease processes and injuries.
> 4. Prevention of or compensation for disability.
> 5. Promotion of well-being.
>
> (Orem, 1985, p. 89)

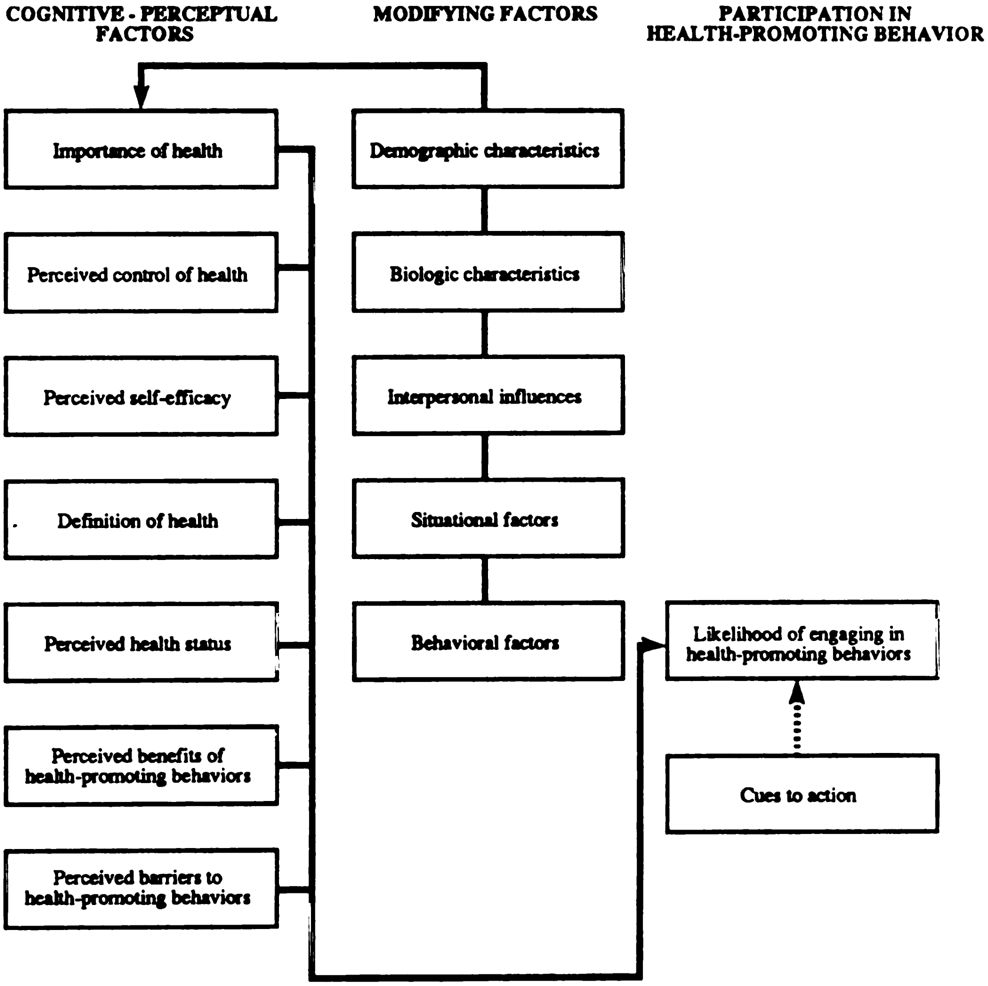
Orem's (1985) theory of self-care, provides a theoretical model for the phenomena of self-care and dependent care (caregiving). In the following section, Pender's (1987) health promotion model is presented. Pender's (1987) health promotion model outlines concepts proposed to describe the determinants of health-promoting behaviors and their interrelationships.

Pender's Health Promotion Model

Pender (1987) makes a clear distinction between health protection and health promotion. Pender (1987) defines health protection as, "decreasing the probability of experiencing illness by active protection of the body against pathological stressors or detection of illness in the asymptomatic stage" (p. 57). Conversely, health promotion is defined by Pender (1987) as, "movement toward a positively valenced state of enhanced health and well-being, through self-actualization and expression of human potential" (p. 57). Pender (1987) identifies the source of motivation as a distinguishing factor between health promotion and health protection. In health protection, the source of motivation is the threat or presence of illness or disease. The source of motivation in health promotion includes: desire for growth, expression of human potential, and quality of life (Pender, 1987).

Self-care is defined by Pender (1987) as, "actions directed toward minimizing threats to personal health, self-nurturance, self-improvement and personal growth" (p. 185). From this definition, self-care may be construed to be both health protective and health promotive. Pender (1987) offers a lengthy discussion of self-care without specifying self-care as health protective or health promotive. Self-care is also not a concept in Pender's (1987) health promotion model. Nevertheless, for the purpose of this study, the definition of caregiver self-care is proposed to be representative of Pender's (1987) concept, "likelihood of engaging in health promoting behaviors" (p. 58). Therefore, self-care practices are identified (for the purpose of this study) as synonymous with Pender's (1987) concept, health promoting behaviors, outlined in the health promotion model.

Pender's (1987) health promotion model, is presented in Figure 2. The model is derived from social learning theory and structurally similar to the health belief model. Structural organization is where the similarity ends, as Pender (1987) emphasizes; "The health belief model is appropriate as a paradigm for health-protecting or preventive behavior, but clearly is inappropriate as a paradigm for health promoting behavior" (p. 44). The inappropriate nature of the health belief model as a



Health Promotion Model

Figure 2. Pender, 1987, p. 58

paradigm for health promotion is based on Pender's claim that, "The negatively valanced states of illness and disease, while relevant to motivation for health-protecting (or preventive) behavior, appear to have little, if any, motivational significance for health-promoting behavior" (p. 57). Instead, the motivation for health-promotive behaviors stem from: desire for growth, need to express human potential, and concern for quality of life.

Pender's (1987) health promotion model is relatively new, and lacks thorough testing to determine how accurately the model explains or predicts specific health promoting behaviors or life style patterns. Acknowledging the lack of research, Pender (1987) notes the model does meet a major criteria of theoretical models, "it is consistent with knowledge to date, yet remains flexible and subject to change as new knowledge is generated" (p. 58-59). one research project based on Pender's health promotion model has been reported on in the literature (Walker, Sechrist, Pender, 1987). A review of the aforementioned study is provided in Chapter III. Clearly, as empirical evidence regarding the determinants of health promoting behaviors becomes available, modifications in Pender's (1987) model may be necessary.

The health promotion model is shown in Figure 2. The model is structurally organized into four areas: cognitive-perceptual factors, modifying factors, cues to action, and participation in health promoting behavior. There are seven cognitive-perceptual factors (importance of health, perceived control of health, perceived self-efficacy, definition of health, perceived health status, perceived benefits of health promoting behavior, and perceived barriers to health promoting behavior) which represent the primary motivational mechanisms for initiating and maintaining health promoting actions (Pender, 1987). The definitions of each of these seven factors is not presented, however, each factor is proposed to exert a direct influence on the likelihood of an individual to engage in health promoting actions (Pender, 1987).

The area titled modifying factors, includes five factors proposed to exert an influence on health promoting behaviors indirectly. These five modifying factors (demographic characteristics, biologic characteristics, interpersonal influences, situational factors, and behavioral factors) exercise an effect acting via the cognitive-perceptual mechanisms, which directly affect the individuals likelihood of engaging in health promoting behaviors (Pender 1987). Definition for the five modifying factors are not provided here. However, in the following section, each modifying factor is defined within the conceptual framework developed for the current study.

Cues to action is the third area in the model proposed to influence health promoting behaviors. Cues to action include internal or environmental tips or hints which inspire or persuade an individual to initiate or continue a particular health promoting behavior (Pender, 1987). Examples of cues to action may include: feeling good, personal health concerns, social or peer pressure, mass media information. Pender (1987) notes, "the intensity of the cues needed to trigger action will depend on the level of readiness of the individual to engage in health promoting activity" (p. 69).

Likelihood of engaging in health promoting behaviors is the final area outlined in Pender's (1987) health promotion model. As mentioned previously, health promoting behaviors are expressions of an individual's actualizing tendencies. Examples of health promoting behaviors outlined by Pender (1987) include: "physical exercise, nutritional eating practices, development of social support, and use of relaxation of stress management techniques" (p. 59). As modeled in figure 2, the likelihood of an individual engaging in health promoting behavior is influenced directly by cognitive-perceptual factors and indirectly by modifying factors. Cues to action represent another source of influences shaping a person's likelihood of engaging in health-promoting behaviors.

A preliminary presentation and discussion of Orem's (1985) theory of self-care and Pender's (1987) health promotion model has preceded. The next section outlines the conceptual framework of the present study, as developed from the aforementioned work of Orem (1985) and Pender (1987). The model concepts are defined and linked to the research variables.

Conceptual Framework

The conceptual framework developed for the research study is depicted in Figure 3. The study framework represents a "blending" of concepts from the Orem (1985) and Pender (1987) models, to achieve a theoretical modeling of caregiver self-care behavior within the context of caregiving. A description of the conceptual framework is given, followed by definitions of the concepts and a review of study variables used to represent the theoretical concepts.

Description of the Conceptual Framework

The conceptual model is bordered by two generic (no gender) stick figures. The figure on the right represents the caregiver, and the figure on the left, the Alzheimer patient. A forked arrow labeled 'A' originates from the caregiver, with one fork directed toward the Alzheimer patient and the other fork curving back toward the caregiver. Arrow 'A' represents self-care provided to the Alzheimer patient by the caregiver (straight arrow), and the caregiver's own self-care demand (curved arrow). The curved portion of arrow 'A' is perforated to represent permeability and openness to environmental effects including the Alzheimer patient.

Within the perforated curve of arrow 'A', is a modified version of Pender's (1987) health promotion model, depicting factors hypothesized to influence caregiver self-care in this investigation. According to the model in Figure 3, seven modifying factors exert an influence on the caregiver's participation in self-care behavior. The seven modifying factors include: demographic characteristics, biologic characteristic, psychological characteristic, situational factor, interpersonal influence, behavioral support, and perceived health status (caregiver). Referring back to Pender's (1987) health promotion model in Figure 2, it is evident that the model designed for the

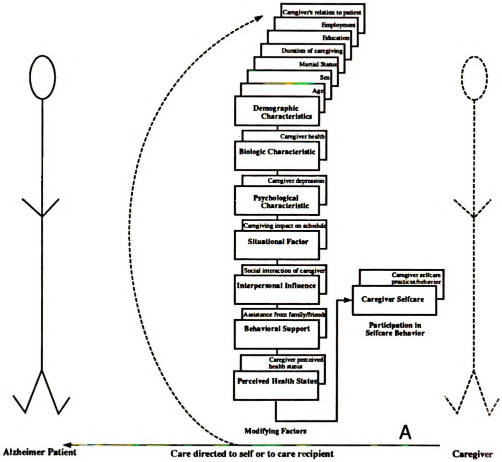


Figure 3. Adaptation of the modified Orem and Pender models to the study variables

current study includes no cognitive perceptual factors or cues to action. Instead, caregiver self-care is modeled as a result of the combined influence of the designated modifying factors.

The interaction of the modifying factors and caregiver self-care is depicted as occurring within the curve of arrow 'A' in Figure 3. However, as mentioned earlier, arrow 'A' is perforated to represent a permeable boundary between the concepts within the curve and the outside environment. Environmental factors (other than environmentally oriented concepts listed as modifying factors) are not addressed in an effort to limit the scope of this research. The influence of the Alzheimer patient is also not specifically addressed in this study. Eliminating Alzheimer patient factors as possible predictors of caregiver self-care was done to limit the variables in the study. Nevertheless, in two separate studies, Alzheimer patient factors such as inappropriate behavior, were found to have no association with caregiver perceived burden (Winogrond et al. 1987; Zarit et al. 1980). What effect specific Alzheimer patient factors have on caregiver self-care practices remains unknown.

Conceptual Definitions

Caregiver Self-care

As modeled in Figure 3, caregiver self-care is the theoretical concept being described or predicted. Conceptually, self-care includes much more than the ability to carry out activities of daily living. Self-care is both an ongoing activity and a competence to be developed (Pender, 1987). "The development and operability of self-care is continuously shaped by genetic and constitutional factors as well as by culture, life experiences, and health status (Orem, 1985, p. 34). In this study, caregiving is suspected to be an additional factor effecting the development and operability of a caregiver's self-care. For the caregiver, self-care must be interspersed among other activities of daily living and demands of caregiving.

Self-care is conceptualized to have both form and content. "The form of self-care is that of deliberate action and its phases. The content of self-care is composed of: the purpose to which self-care is directed, the need for self-care, and courses of action that are effective in meeting the self-care need" (Orem, 1985, p. 106). This research investigation is a contribution to discovering the components of caregiver self-care as conceptualized above.

Pender (1987) focuses self-care for older adults on maximizing independence, vigor, and life satisfaction. Many benefits of self-care in older adults are reported by Pender (1987), "physical exercise to maintain or increase cardiac and pulmonary functioning, weight control to enhance mobility, exercise to enhance self-esteem and decrease depression and anxiety" (Pender, 1987, p. 189). Though untested, the benefits of self-care for older adults in a caregiving role may prove to be dramatic in supporting and maintaining the patient/caregiver relationship and environment.

As defined in Chapter One, caregiver self-care involves generic activities performed deliberately by caregivers in the areas of: nutrition, disease prevention, exercise, stress reduction and relaxation, for the purpose of achieving or maintaining good health. Engaging in self-care to enhance health and well-being may require old patterns of behavior be extinguished and new patterns of behavior learned (Orem, 1985). Adjusting successfully to the caregiving role may also require that caregivers learn new behaviors, ideally, health promoting ones.

Demographic Characteristics

Demographic characteristics, is the first of seven concepts identified as 'modifying factors' in Figure 3. The order of concepts labeled 'modifying factors' is arbitrary and not representative of their contribution in influencing caregiver self-care. As defined for this study, demographic characteristics are parameters of the study sample proposed within the model as effecting patterns in the caregivers self-care.

In regard to demographic variables and their impact on health promoting behavior, Pender (1987) notes, "The extent to which demographic characteristics influence participation in health behavior and the similarities and differences between demographic influences on health protecting versus health promoting behavior need to be determined" (p. 66). In a study on investigating strain among caregivers, Cantor (1983) warns, "homogenization of caregiver demographics such as: sex, age, health, and work status, has resulted in obscuring differences among groups of caregivers and the types of stress each group experiences in the process of giving assistance" (p. 597). It is particularly salient to investigate demographics in the research of caregiver self-care. The unique situation of each caregiver must be evaluated to develop an appropriate and effective program to initiate or support caregiver self-care behavior.

Biologic Characteristics

In the health promotion model, Pender (1987) defines the concept, biologic characteristics as, " a number of biological factors found to be related to exercise adherence" (p. 67). Pender (1987) cites the research based, inverse relationship, between total body weight and exercise program adherence. That is, as total body weight increases, exercise program adherence decreases.

As a concept in the framework developed for this study, biologic characteristics represent an objective measure of the caregivers health. Due to a lack of prior research, the concept, biologic characteristics, is included in this model on conjecture that the health (objective measure) of a caregiver may influence the caregiver's level of self-care.

Unlike self-care, health has been used previously as a variable in studying the affect of caregiving on caregivers. Two studies, Pratt et al. (1985) and Pratt et al. (1987) found caregiver burden levels were significantly related to caregiver health status. Caregivers judged to be in good health had lower burden scores than those caregivers judged to be in poor health

(Pratt et al. 1985). By utilizing an objective measure of caregiver health to represent the concept, biologic characteristics, caregivers in objectively poor health are distinguished from caregivers who are more subjectively concerned about their health. The latter group of caregivers may tend to focus on medical problems as one of the few ways of receiving a sanctioned relief from caregiving responsibilities (Haley, 1986).

Psychological Characteristics

Pender's (1987) original health promotion model, pictured in Figure 2, does not include the concept, psychological characteristics, as a modifying factor. In altering Pender's model for the purpose this study, an additional modifying factor, psychological characteristics, is added as pictured in Figure 3. Conceptually, psychological characteristics represent caregiver mental health, expressed in this study as a measure of caregiver depression.

Depression is common among caregivers. Rabins et al. (1983) questioned the primary caregivers of a group of demented patients and found 87% reported chronic fatigue, anger, and depression. Haley (1986) investigated the occurrence of depression in Alzheimer caregivers and found, "Caregivers who subjectively report that patient behavior problems and disability are stressful to them , and who report little confidence in their ability to handle these problems, appear significantly more depressed. These measures of caregivers appraisals are more consistently related to caregiver depression than life satisfaction or health" (p. 28).

There is a lack of research exploring any possible correlation between caregiver depression and caregiver self-care. It is the premise in this study that caregiver self-care may be effected by the presence or absence of caregiver depression. The rational for including this psychological concept in the model is based on the frequency of reported depression in caregivers and the contention that mental state influences the caregiver's participation in self-care.

Situational Factor

In Pender's (1987) health promotion model, the concept situational factors represents important situational or environmental determinants of health promoting behavior. As Pender (1987) states, "Individuals may wish to behave in ways that promote health, but environmental constraints prevent access to healthful options" (p. 68). Environmental constraints identified by Pender (1987) include: poor selection of healthful "fast food", employers providing no time or access to exercise, vending machines in schools stocked with food low in nutritional value.

The concept situational factor, is included in the model for this study as outlined in Figure 3. Situational factor is defined in this model as a measure of the impact caregiving has on the caregiver's normal, daily routine. The impact of caregiving on the caregiver's schedule includes measures of: the amount of care required, the time involved, and the elimination of other caregiver roles as a result of caregiving. The degree of interruption caregiving produces in the caregiver's normal schedule is hypothesized to have an affect on the caregivers participation in self-care. No previous research was found in this area. Nevertheless, it is logical to anticipate that unpredictable caregiving duties may impede the caregiver's efforts to perform consistent self-care activities.

Interpersonal Influences

In the health promotion model, (Pender, 1987) interpersonal factors proposed to influence health-promoting behaviors include: "expectations of significant others, family patterns of health care, and interactions with health professionals" (p. 67). These interpersonal influences receive support from research findings regarding their impact on health behavior (Pender, 1987).

As diagrammed in the conceptual model of this study, interpersonal influences is proposed as a modifying factor of caregiver self-care. In this study, interpersonal influences is defined as a measure of the caregiver's social interaction; assessed by evaluating the nature and frequency of contacts caregivers have with others in their environment (Given and Collins, 1987).

As a concept, interpersonal influences may be thought of as one arm of the larger construct, social support. Cobb (1976) defines social support as, "the information leading an individual to believe that he or she is cared for and loved, esteemed, and a member of a network of mutual obligations" (p. 300). Previous studies have found social support to be a mediator of caregiver burden (Fengler and Goodrich, 1979; Gilhooly, 1984; Morycz, 1985; Zarit et al. 1980). Recent studies have investigated proposed elements of social support in an effort to identify what impact the components of this larger construct have on caregiver well-being. Scott, Roberto and Hutton (1986) examined the instrumental and social emotional support provided by families to the primary caregivers of Alzheimer's patients. The types of assistance from family that were most appreciated by cargivers included: ". . . visits, and having persons stay with the patient so that the caregiver could take a trip, rest, run errand, or get out of the house for social activities" (Scott et al. 1986, p. 348).

In regard to caregiver social networks, interpersonal influences refer to the caregiver's degree of social isolation or connectedness. Haley (1986) compared Alzheimer caregivers and an age-matched control group and reports:

> Although there is little evidence that the size of social network and casual contacts is decreased, (as a result of caregiving) caregivers are clearly severely limited in activity. Activity with friends appears to be more strongly affected than activities with other family members. Few caregivers are able to take time away from their patient for even a brief vacation.
> (Haley, 1986, p. 23)

The loss of interpersonal transactions can lead to role constriction and eventual role fatigue (Goldstein et al. 1981). Data from a study by Goldstein et al. (1981) indicates, "when virtually all the individual's activities center around a single role (caretaking) and interpersonal transactions are primarily with one other person (the patient), the opportunities to obtain role relief (i.e., to shift to other roles and to interact with a variety of other persons) are minimal, and results in a kind of 'cabin fever' or role fatigue" (p. 26).

Clearly the concept interpersonal influences is documented as a mediator of caregiver burden and well-being. What is unknown, and the focus in this study, is the impact interpersonal influences have on caregiver self-care behavior. The lack of prior research to support or refute any correlation between caregiver self-care and interpersonal influences is justification to include the concept in the framework of this study.

Behavioral Support

The final modifying factor outlined in the conceptual framework of the study (Figure 3) is titled, behavioral support. For the purpose of this research, behavioral support is defined as a measure of instrumental support for the caregiver, determined by assessing the amount of assistance family and friends provide in performing tasks for the caregiver (Given and Collins, 1987). Behavioral support focuses on the degree of tangible assistance, aid, or information, the caregiver receives from friends or family.

In the conceptual model of the study, behavioral support is anticipated to influence caregiver self-care behavior indirectly as a modifying factor. No prior research on the relationship between behavioral support and caregiver self-care was found. Nevertheless, behavioral support (as a measure of instrumental support) has been utilized to investigate other dimensions of caregiver well-being. Gilhooly (1984) found caregiver satisfaction with help received from relatives, was significantly correlated with caregiver mental health ratings and morale. Data from two studies by Zarit et al. (1980) and Zarit (1982) support the finding that it is the caregivers perception of support from family and friends rather than the actual amount of support, which modifies the caregiver's feeling of burden.

It is logical to speculate that assistance from family and friends may provide the caregiver greater freedom of time and responsibility. Therefore allowing the caregiver to pursue personal needs and interests, such as self-care. For the purpose of this study an objective measure of behavioral support (amount of assistance from family and friends) is evaluated to determine the effect of behavioral support on caregiver self-care.

Perceived Health Status

As depicted in Figure 3, perceived health status is the single cognitive perceptual factor (from Pender's original health promotion model) proposed in the conceptual framework for this study. Perceived health status was incorporated as a modifying factor in this study framework to achieve a better "fit" of theory and the operationalized study variables. As discussed previously, Pender (1987) outlines seven cognitive-perceptual factors in the original health promotion model. The use of a single cognitive-perceptual factor in this study was not done by choice, but was a constraint of using secondary data. Clearly, the opportunity to include more of Pender's (1987) original cognitive-perceptual factors would strengthen the conceptual framework of the study.

The premise of the concept 'perceived health status' is simple, "feeling good may be a source of motivation for taking actions that increase personal health status" (Pender, 1987, p. 64). In a study done on non-caregivers, 45-69 years of age, Palmore and Luikart (1972) found that, "self-rated health correlated more highly with life satisfaction than did activity level, organizational or social activity, productivity, or career anchorage" (p. 78). Other studies done on non-caregiver samples conclude that perceptions of being in good health are repeatedly associated with: performance of health promoting behaviors (Christiansen, 1981); intentions to attain or maintain recommended weight (Pender and Pender, 1986), and increased probability of continuing exercise behavior (Dishman, Sallis, Orenstein, 1985).

Caregiver perceived health status has been utilized in research pertaining to caregivers also. Pratt et al. (1987) comments, "caregivers' rating of their current health status were significantly related to patient residence, with caregivers to institutionalized relatives significantly more likely to rate their current health status as 'fair' or 'poor'" (p. 105). Caregiver burden levels are also reported to be significantly and inversely related to caregiver health status, as reported by Pratt et al. (1985).

In a study of Alzheimer caregivers and a matched control group, Haley (1986) was unable to determine, "whether caregivers are in objectively poorer health than the controls, or whether caregivers are more subjectively concerned about their health" (p. 23). Haley (1986) notes a hazard in using, perceived health status, as a concept ". . . caregivers may tend to focus on medical problems as one of the few ways of receiving a sanctioned relief from caregiving responsibilities" (p. 24).

The link between perceived health status and self-care behaviors is confirmed in research on non-caregiving samples. This same link (perceived health status and self-care behavior) has not been investigated among caregivers; furthermore, caregiver perceived health status may be confounded as a result of caregiving (Haley, 1986). For the purpose of this study, caregiver perceived health status is evaluated to determine what effect a caregiver's perceived health status has on the caregiver's performance of self-care behaviors.

The organization of this study is such that the study variables are introduced and defined in Chapter One; the framework and theoretical concepts presented and defined in Chapter Two, with operational definitions of the study variables presented in Chapter Four. To clarify the relationship of theoretical concepts and study variables, each concept and its corresponding study variable or variables is briefly outlined in the following table, Table 2.1.

Table 2.1

Relationship of Theoretical Concepts and Study Variables.

Theoretical Concept	Study Variable
caregiver self-care	caregiver self-care practices/behaviors
demographic characteristics	caregiver: age, sex, marital status, duration of caregiving, education, employment, familial relation to patient
biologic characteristic	caregiver health
psychological characteristic	caregiver depression
situational factor	impact of caregiving on caregiver's schedule
interpersonal influence	social interaction of caregiver
behavioral support	amount of assistance from family/friends
perceived health status	caregiver perceived health status

Orem's Theory of Nursing Systems

As stated earlier, Orem's (1985) theory of nursing systems is used to support the link between this research and nursing theory/practice. The importance of combining theory with practice is highlighted by Weekes (1986):

> . . . it is suggested that nursing science approach observation and theory as a dialectic unity of opposites involving (1) clinical observations evaluated in light of available theory (2) present knowledge (theory) evaluated from the perspective of clinical observations, and (3) completed studies evaluated in light of both. This approach allows, as well as corrects, for the fact

> that observation is theory laden. In addition, it clearly explicates the relationship between theory and observation; that is, theory drives observation, and observational findings shape the development of theory, and the two form the core of an observational practice discipline. (p. 19)

In short, the clinical nursing application of the study is guided by the theory of nursing systems as developed by Orem (1985). As stated earlier, Orem's (1985) general theory of nursing is constituted from three related theoretical constructs: "the theory of self-care deficit, the theory of self-care, and the theory of nursing system(s)" (p. 34). Orem's (1985) theory of self-care was discussed earlier in this chapter. Orem's (1985) theory of nursing system(s) is presented here to stress the relevance of this research to nursing practice.

Explaining how persons (caregivers) can be helped through nursing, Orem (1985) proposes a theory in which, "the product of nursing practice is a nursing system(s) through which the capability of patients to engage in self-care is regulated and self-care is continuously produced" (p. 34). According to Orem (1985), "nursing system can be used in a general way to stand for all the actions and interactions of nurses and patients in nursing practice situations" (p. 148). In concrete terms, the elements of nursing systems are: "the persons who occupy the position of nurse and the status of nurse's patient and the events that transpire between them" (Orem, 1985, p. 148).

Within the theory of nursing system(s), Orem proposes a typology of nursing systems:

1. wholly compensatory nursing systems
2. partly compensatory nursing systems
3. supportive-educative nursing systems

(Orem, 1985, p. 152)

Each system is explained by Orem (1985) to be a result of the question: "Who can or should perform those self-care actions that require movement in space and controlled manipulation?" (p. 152). If the answer is the nurse, the system is called wholly compensatory, because of the patient's total inability to fulfill his or her own self-care requirements. If the answer is the patient can perform some, but not all self-care requisites, the system is termed partly compensatory. If the answer is that the patient can and should perform his or her own self-care, the system is titled supportive-educative.

The nursing system of interest in this study is the supportive-educative system. Caregivers are primarily individuals who "can and should" perform their own self-care activities. In a supportive-educative nursing system, the nurses role is not to do for the patient. Instead, it is the nurse's responsibility to teach, guide, support, and assist the patient in achieving his or her therapeutic self-care demand (Orem, 1985). As Orem (1985) notes, "this is the only system (supportive-educative) where a patient's requirements for help are confined to decision making, behavior control, and acquiring knowledge and skills" (p. 156).

By definition, it appears the supportive-educative nursing system is most appropriate for assisting caregivers with their self-care requisites. Nevertheless, the nurse must recognize Orem's (1985) nursing systems as dynamic and select the system, or sequential combination of systems, with the optimum effect in achieving the caregiver's therapeutic self-care demand. For example, suppose an elderly female caregiver suffers a fall which results in a hip fracture. The caregiver will require a wholly compensatory nursing system while hospitalized and initially post-op due to the immobilized hip. A partly compensatory nursing system will evolve as the caregiver begins physical therapy to regain motion and weight bearing of the repaired hip. Once released from the hospital, the caregiver can benefit from a supportive-educative nursing system. The nurse can use the supportive-educative system to counsel the caregiver on ways to maximize her recovery and health within the context of caregiving. Such counseling may include topics such as: nutrition, exercise, weight control, time and resource management, and stress reduction. The caregiver may require teaching, support or consultation in one or all of the above areas to achieve her personal therapeutic self-care demand.

Professional nurses in primary health care settings are in an ideal position to identify the self-care needs of caregivers. Caregivers often accompany the patient in their charge to health care visits. The astute clinician can use this time as an opportunity to assess the caregivers level of self-care. Once an assessment is made, the nurse can negotiate with the caregiver to determine what nursing system or systems will best facilitate the desired self-care outcome.

Summary

The content of Chapter Two has included: a discussion of the conceptual framework of the study, definitions of framework concepts, and an explanation of the association between this research and nursing theory/practice. The focus of Chapter Three is a comprehensive review of the literature pertinent to the subject and purpose of this study.

CHAPTER III

Review of the Literature

Overview

Relevant literature pertaining to the framework concepts and associated study variable(s) is presented in this chapter. The purpose of this chapter is to review research findings and narrative articles involving efforts to analyze caregiver self-care practices and variables influencing caregiver self-care. Because the focus of this study is Alzheimer caregivers' self-care, an effort is made to review literature utilizing samples of caregivers of Alzheimer patients. Nevertheless, additional articles and data from other caregiving populations are used as needed to review the concepts and variables outlined in this study.

The chapter is divided into sections. Each section is labeled corresponding to the study concepts outlined in Chapter Two. Therefore, Chapter Three is divided into the following sections: caregiver self-care, demographic characteristics, biologic characteristic, perceived health status, psychological characteristic, situational factor, interpersonal influence and behavioral support. Within each section, research and literature specific to the study concept, and associated study variable(s) is reviewed. Preceding the aforementioned sections is a brief review of Pender's (1987) health promotion model. Following the review of study concepts is a synopsis of the Alzheimer caregiver literature from a nursing perspective. The chapter ends with a brief discussion of the "status" of this study in relation to prior Alzheimer caregiver research.

Pender's Health Promotion Model

As presented in Chapter Two, a modified version of Pender's (1987) health promotion model represents the 'core' of the conceptual framework developed for this study. Dovetailing with the purpose of the study, Pender's (1987) health promotion model functions to:

> 1. Introduce order among concepts that may explain the occurrence of health-promoting behavior.
>
> 2. Provide for the generation of hypotheses to be tested empirically.
>
> 3. Integrate disconnected research findings into a coherent pattern.
>
> (Pender, 1987, p.57)

Pender's health promotion model is new, (revised in 1987) and its empirical adequacy and testability have been reported only once in the literature (Walker, et al. 1987). In an effort to develop a valid and reliable instrument to measure health-promoting life-style, Walker, et al. (1987) constructed the Health-Promoting Life-sytle Profile (HPLP) based on the theory of Pender's health promotion model. Walker et al. (1987) evaluated the HPLP on a sample of well adults using item analysis, factor analysis, and reliability measures. Although ten separate but related dimensions originally composed the HPLP, only six dimensions were supported by the factor analysis and reliability estimates (Walker, et al. 1987). Further evaluation of the HPLP with different populations appears warranted. Nevertheless, the

HPLP, "appears to have sufficient validity and reliability for use by researchers who wish to describe the health-promoting component of lifestyle in various populations, to explore correlates or determinants of health promoting lifestyle, or to measure changes in health promoting lifestyle as a result of interventions" (Walker, et al. 1987, p. 80).

Pender's (1987) health promotion model has not been utilized with a sample of caregivers (Alzheimer's or otherwise). Furthermore, the results obtained in this study, using a modified version of Pender's (1987) model, cannot be construed as representative of results that may be obtained using Pender's (1987) original health promotion model with a caregiving population.

Just as Pender's (1987) model lacks thorough empirical testing, the conceptual model developed for this study lacks testing. Nevertheless, research and literature pertinent to the concepts in the study framework can be reviewed to support or challenge the validity of the proposed model. The first study concept reviewed is, caregiver self-care.

Caregiver Self-Care

In this section, literature pertinent to the concept 'caregiver self-care' is presented. To review briefly, 'caregiver self-care' is the "correlational" concept in the conceptual model. 'Caregiver self-care practices/behaviors' is the single dependent variable of the study, and in the analysis the dependent variable (caregiver self-care) is regressed on the various independent variables.

The concept 'caregiver self-care' is pivotal to the uniqueness of the current study. Among the literature reviewed for this study, no prior research was found in which Alzheimer caregivers' self-care was specifically analyzed or assessed within the context of caregiving. The majority of research on Alzheimer caregivers is devoted to the definition and measure of the construct 'burden' (Cantor, 1983; Chenoweth and Spencer, 1986; George and Gwyther, 1984; Jenkins et al. 1980; Montgomery et al. 1985; Poulshock and Deimling, 1984; Zarit et al. 1980) and how caregivers cope with the impact of burden (Barnes et al. 1981; Colerick and George, 1986; Gilhooly, 1984; Johnson and Catalano, 1983; Kahan et al. 1985; Morycz, 1985; Pratt et al. 1985; Pratt et al. 1987).

Admittedly, some components of caregiver burden defined in the literature may also be defined as components of caregiver self-care (i.e., caregiver: amount of sleep, social activities, leisure activities, use of psychotropic drugs). Nevertheless, the objective of this study was not to examine or define the negative impact of caregiving (burden) on Alzheimer's caregivers, but to investigate what relationship specific independent variables have with the caregivers' reported self-care practices. Therefore, the caveat is made, that, much of the literature cited in this review involves studies utilizing concepts or variable(s) outlined in this study, with Alzheimer caregiver variables other than self-care. For example, the study concept 'demographics' includes the study variables of caregiver: age, sex, marital status, education, employment, relation to patient, duration of caregiving. Optimally, the literature review of the concept 'demographics' would include studies analyzing the demographic variables (caregiver age, sex, etc.) and Alzheimer caregivers' self-care practices. Unfortunately, studies of Alzheimer caregivers' self-care practices were not found. Therefore, the demographic variables must be reviewed via research completed on Alzheimer caregivers, involving variables other than caregiver self-care. Having clarified the aforementioned caveat for this literature review, the literature review of the concept 'caregiver self-care' continues.

It is a fact that women comprise a majority of the older population and that knowledge about the health and self-care practices of older women is currently inadequate (McElmurry and LiBrizzi, 1986). Statistics from demographic studies support the hypothesis that men are biologically weaker than women, experiencing higher mortality rates from the moment of conception (Cowling and Campbell, 1986). The current estimated life expectancy for males is 71.8 years, opposed to a life expectancy of 81 years for females (Carnerali and Patrick, 1979). Acknowledging the gender differences in mortality statistics, a solid base of empirical research also exists, indicating a variety of behavioral factors that significantly influence morbidity and mortality among both genders (Belloc and Breslow, 1972; Metzner, Carmen, and House, 1983; Reed, 1983; Wiley and Camacho, 1980). Nearly ten years ago, (1979) the Surgeon General of the United States issued a report estimating that as much as half of the country's mortality may be due to unhealthy behavior (U.S. DHEW, 1979). As evidence accumulates concerning the impact of personal behavior on health, the quest to understand the determinants of health behaviors (self-care) intensifies (Hubbard et al. 1984; Pender and Pender, 1986).

In an effort to determine the use and effectiveness of coping strategies in reducing Alzheimer caregiver stress, Scott et al. (1987) analyzed three coping strategies (caregiver: recreational contacts, sleep, and maintenance of own health) which also match the definition of self-care utilized in this study. None of the three aforementioned strategies were reported as commonly used to reduce stress. Regarding effectiveness, a disruption in sleeping patterns, (resulting in less sleep) and a change in recreational contacts, (resulting in fewer contacts) both contributed to increased caregiver stress.

George and Gwyther (1986) examined four dimensions of Alzheimer caregiver well-being: physical health, mental health, financial resources and social participation. Results of the George and Gwyther (1986) study indicate that relative to random community samples, caregivers are most likely to experience problems with mental health and social participation. The questions used to assess mental health and social participation in the George and Gwyther (1986) study, are similar to questions concerning self-care (i.e., stress symptoms?, use of psychotropic drugs?, time spent in hobbies or relaxing?, visits or phone contacts with family/friends?). It is important to note that in both the Scott et al. (1987) and George and Gwyther (1986) studies, had the caregivers received support in the self-care areas identified above, a more desirable outcome may have been observed (i.e., less stress and better well-being).

Gwyther and Matteson (1983) report:

> Caregivers state their major coping stresses as their own fatigue and lack of time for themselves and their other role responsibilities. They (the caregivers) often respond best to a professional "prescription" for respite. . . They (the caregivers) need a "prescription" to take care of themselves in order to continue their availability to the Alzheimer patient. (p. 95, 110)

The quote above addresses the need for caregiver self-care behavior, and offers a technique for giving the caregiver "permission" to pursue self-care activities.

A logical rational for this investigation of Alzheimer's caregivers' self-care, is the limited amount of research currently available. More compelling, are the results of existing studies providing empirical evidence of abuses and/or deficits in caregiver self-care or health status as a product of caregiving (Colerick and George, 1986; George and Gwyther, 1986; Haley, 1986; Scott et al., 1987).

This study is designed to expand and improve on previous research by:

-investigating independent variables alluded to in the literature as items related to caregiver self-care

-utilizing a homogeneous sample in regard to patient/caregiver must be related and reside in the same place

-sample involves only Alzheimer's caregivers

The focus of this study is aimed at analyzing caregiver self-care practices (not caregiver health status) and how various independent variables correlate with caregiver self-care. Because there appear to be no prior research studies similar to this one in the current literature. The study results can be used in a preliminary fashion to gain some insight into the issue of caregiver self-care.

Demographic Characteristics

In this section, research and literature pertaining to the concept 'demographic characteristics' is presented. Study variables associated with the concept 'demographic characteristics' include caregiver: relation to patient, marital status, age, sex, employment, education, and duration of caregiving.

The status of the concept 'demographic characteristics' is accurately assessed by Gwyther and George (1986) who comment, "We are only now at the point that the importance of heterogeneity among caregivers is becoming recognized" (p. 245). Several consequential sources of variation in the Alzheimer caregiver population are beginning to receive attention in the literature.

Worcester and Quayhagen (1983) utilized demographic variables in an effort to predict the level of caregiver satisfaction in providing care. The majority of carers in the Worcester and Quayhagen study were caring for physically rather than cognitively impaired patients. Nevertheless, the following demographic data emerged from the study:

> - The older the caregiver, the more satisfaction reported in the caregiving role.
> (accounted for by the fact that older caregivers may be more comfortable in the caregiver role than younger caregivers)
>
> - The longer the caregiving duration, the less satisfaction reported in caregiving.
> (accounted for by the likelihood that as the duration of caregiving increases, the age and problems of the client increase, making caregiving more difficult)
>
> - Lower income carers were more satisfied in the caregiving role than carers of the middle class.
> (supported in other studies that show lower socioeconomic classes view the care and responsibility of relatives as less burdensome than middle classes)
>
> (Worcester and Quayhagen, 1983, p. 67)

Each of the demographic variables outlined in the study will be reviewed separately beginning with, 'the relationship of the caregiver to the Alzheimer patient'. The demographic variable 'caregiver marital status' will be subsumed in the review of the first variable, 'the relationship of the caregiver to the Alzheimer patient'.

The relationship of the caregiver to the Alzheimer patient

Cantor (1983) reported the closer the caregiver/patient bond, the greater the amount of strain on the caregiver, with spouses being at highest risk. Gilhooly (1984) found caregiver/patient relationship was significantly related to caregiver mental health --the greater the "distance" in the relationship, the better the caregiver's mental health. Gilhooly (1984) also investigated caregiver morale, but found no correlation between patient/caregiver relationship and caregiver morale.

In a study by George and Gwyther (1986) it was reported that spousal caregivers of Alzheimer patients exhibit: low levels of well-being, poor self-rated health, and significantly lower incomes than adult child and other caregivers. The fourth area analyzed in the George and Gwyther (1986) study included, social activity. Spouse and adult child caregivers were identical in this area, (social activity) with significantly lower values than other (non-family) caregivers (George and Gwyther, 1986).

In contrast, Colerick and George (1986) found spousal caregivers report lower use of stress-reducing drugs and high levels of life satisfaction, compared to adult child caregivers. Colerick and George (1986) explain this finding as a result of spousal caregivers accepting the role and realizing that the caregiver role has, and continues to occupy a central role in the spouse's life. Spousal caregivers are known to devote greater amounts of time to caregiving, (Caserta et al. 1987) and are the least likely caregivers to relinquish caregiving duties to professionals, even at great cost to their own health and well-being (Pratt et al. 1987).

The second most common Alzheimer caregiver is a female adult child or daughter-in-law (Shanas, 1979). Daughters or daughters-in-law assuming the caregiving role, often experience high levels of stress due to their other role responsibilities as mothers, wives, and employees (Colerick and George, 1986). The adult child caregiver is reported to have an income above the average of other caregivers and therefore is more likely and able to exercise the option of institutionalization, should caregiving become overwhelming (Colerick and George, 1986).

A study by Zarit et al. (1980) serves to highlight the lack of consistent findings in regard to the effect of the caregiver/patient relationship. Zarit et al. (1980) found no difference in the burden perceived by spouses -vs- adult child caregivers, even when controlling for the patient's level of impairment. The lack of consistent findings in many areas of Alzheimer caregiver literature may be partially attributed to the lack of consistency in defining and operationalizing constructs such as burden, stress, strain (Jenkins, Parham, and Jenkins, 1985).

Caregiver Sex

Just as there are statistics to support the statement that "aging is a women's issue", (McElmurry and LiBrizzi, 1986) there are also statistics providing empirical evidence that caregiving is a women's issue (Goodman, 1986). Because of persistent sex-role differences, and greater female life expectancy, women are much more likely than men to assume responsibility for providing direct care (Brody, 1981; Shanas, 1979; Troll, 1971). The current research available on gender difference and the Alzheimer caregiver is limited, yet informative.

In a study of impact of caregiving on caregivers, Gilhooly (1984) reported male caregivers having higher morale than female caregivers. Gilhooly (1984) offers three possible explanations for the morale gender difference:

> 1. Men in the sample were less emotionally involved with their patients than female caregivers.
>
> 2. Men in the sample were more willing to go out of the house, leaving the patient unattended (less social isolation.
>
> 3. Men may be less willing to admit distress, even when it is felt. (p. 41)

Zarit et al. (1981) found wives to be more burdened and more likely to institutionalize than caregiving husbands. In addition, Morycz (1985) reported that although males were not found to be any less desirous of institutionalizing the Alzheimer patient, strain (perceived by the male caregiver) did not predict the desire to institutionalize for the male caregivers. The aforementioned studies appear to support the contention that male caregivers are more resilient than females, in coping with strain as a consequence of caregiving. The current study will provide insight into gender difference and self-care practices of caregivers. Perhaps some of the positive outcomes observed in male caregivers by previous researchers may be explained by the study variable 'caregiver self-care practices'.

Lastly, in the often cited study by Fengler and Goodrich (1979), the morale of wives of elderly disabled men, although overall fairly low, was higher when they perceived their income as adequate and when they were not employed full-time. The degree of disability of the husband was not a factor in differentiating the wife's morale.

Caregiver Age

Caregiver age is commonly collected as part of the sample demographics in Alzheimer caregiver studies. Other than a notation of frequency in the 'results' section, caregiver age has only indirectly received analysis as a variable in the Alzheimer caregiver experience. Cantor's (1983) study of strain among caregivers, noted age as a function of spouse caregivers -vs-adult child caregivers. In Cantor's (1983) work, spousal caregivers were the high risk group due to: increased age, poor health, low income, and an increased potential for isolation and psychological stress (as the husband/wife dyads often reside alone). In contrast, adult child caregivers were: middle aged, married, living with family, working, and had higher incomes (Cantor, 1983).

Caregiver age is reported to be a factor in Alzheimer patient institutionalization, with younger, non-spouse, caregivers more likely to relinquish care than older, spouse, caregivers (Colerick and George, 1986). Adult child caregivers may exercise the option of institutionalization more frequently. However, these younger caregivers also report more feeling of guilt, inadequacy, and use of psychotropic drugs, post-institutionalization (Colerick and George, 1986; Pratt et al. 1987). The distress observed in adult child caregivers post-institutionalization, may be a result of the caregivers' informal social support network dissipating upon institutionalization of the patient (Colerick and George, 1986).

Caregiver Education

Measures of caregiver education are often collected in the demographic section of Alzheimer caregiver studies. In reviewing the literature for this study, no research was found in which caregiver education received more than a tabulation of frequency in the 'results' section of the study (Cantor, 1983; Caserta et al. 1987; Chenoweth and Spencer, 1986; Colerick and George, 1986; George and Gwyther, 1986; Morycz, 1985; Pratt et al. 1985). In the aforementioned studies, the majority of caregivers were high school graduates or above. This level of education may be a function of where the samples were collected (i.e., Alzheimer support groups, ADRDA chapters) and reflect the intellect of persons already seeking additional knowledge about Alzheimer's disease and its management.

It is logical to anticipate that a variable such as 'caregiver education' may contribute much in a study designed to analyze caregiver self-care. While education or knowledge of self-care practices in no way assures participation, knowledge (of self-care) is a required antecedent for participation in self-care practices.

Caregiver employment

Caregiver employment is a variable that has received limited analysis in the caregiver literature. The variable 'caregiver employment', is also commonly tabulated in caregiver studies, but further analysis of caregiver employment is reported in only a few studies.

Colerick and George (1986) found caregiver employment to be a factor in the type of care provided. Continuous, in-home care was more likely when the caregiver was an elderly, unemployed spouse (Colerick and George, 1986). Conversely, institutional care was more likely when the caregiver was an employed daughter (Colerick and George, 1986). Gilhooly (1984) reported employed caregivers of dementia patients have somewhat higher morale and better mental health then unemployed caregivers. Conversely, Fengler and Goodrich (1979) reported the morale of wives of disabled men to be higher when they were not employed full time. The lack of consistent findings in this area may be attributed to different: operational definitions of variables, sample populations, and sample size.

Caregiver unemployment is reported to contribute to the development of caregiver 'role fatigue', a phenomena described by Goldstein et al. (1981). Role constriction and subsequent role fatigue, occurs when an individual's range of roles is sharply reduced and the individual is restricted (for all practical purposes) to only one role (i.e., caregiving) (Goldstein et al. 1981). Thus, as the caregiver reduces his or her multiple roles in an effort to continue their caregiving duties, they become more at risk for 'role fatigue'.

Duration of Caregiving

Duration of illness, (Alzheimer's disease) rather than duration of caregiving, has received more frequent analysis in the caregiver literature. Grad and Sainsbury (1963) found that families caring for elderly patients suffering chronic illnesses exhibited greater burden than those coping with acute illnesses. Similarly, Newbigging (1981) found that duration of dementia was inversely correlated with caregiver morale.

In contradiction to the aforementioned studies, Gilhooly (1984) found that the longer the carer had been giving care, the higher his or her morale and mental health ratings. The results of Gilhooly's (1984) study are surprising, however, the sample size was small (n=37) and the Gilhooly herself acknowledges the measures used may have been too general and masked the effects of specific features of Alzheimer's disease. Gilhooly (1984) offers two explanations for the unexpected results:

> 1. The 'survival effect' which is evoked by caregivers who divorce themselves from the psychological strain of caregiving to protect their own sense of well-being.
>
> 2. The longer the time the caregiver has to learn to cope and adjust, the more likely a positive outcome will prevail. (p. 42)

In opposition to the aforementioned studies on duration of caregiving, Machin (1980) found no relationship between years spent caring for an elderly relative and score for caregivers on burden, strain, or life satisfaction scales. The elderly being cared for in Machin's (1980) study were not specifically identified as Alzheimer patients.

In summary, the concept demographic characteristics, represents a "mixed bag" of research on the study variables of caregiver: relation to patient, marital status, age, sex, employment, education, and duration of caregiving. Each of the demographic variables reviewed merit further research to validate or refute the results of earlier studies. For the purpose of this study, the demographic variables will be combined to represent a "net" influence or relationship with caregiver self-care. Ideally, each of the demographic variables could be explored for their unique relationship with the dependent variable, caregiver self-care practices.

Biologic Characteristic

In this section, research and literature pertaining to the concept 'biologic characteristic' is reviewed. The study variable associated with the concept 'biologic characteristic' is 'caregiver health'. Caregiver health was defined previously in this work as: the number of chronic diseases or physical problems the caregiver experiences, and the degree to which these diseases or problems negatively impact the caregiver's life-style.

Reports of declining caregiver health as a result of caregiving are frequent in the literature (Charlesworth, Wilkin, and Dune, 1983; Colerick and George, 1986; George and Gwyther, 1986; Haley, 1986; Johnson and Catalano, 1983; Levin, 1983; Pratt et al. 1987; Pratt et al. 1985). Caregiving as a potentially high-stress situation, and the prolonged dependency of the Alzheimer patient, combine to threaten the health status of the primary caregiver (Johnson and Catalano, 1983).

Haley's (1986) measure of Alzheimer caregiver health is closely aligned with the caregiver health variable defined in this study. To compare Alzheimer caregivers' health with a matched control sample, Haley (1986) utilized the Pennebaker Inventory of Limbic Languidness, (PILL) a 54 item, self-report, inventory of common physical symptoms. In addition to the PILL, Haley (1986) administered the Health Status Questionnaire, (HSQ) to collect a measure of chronic conditions and self-reported health problems among the caregiver sample. Haley (1986) reported caregivers have significantly poorer health than controls on a number of variables. Caregivers rated their health as poorer than controls, and caregivers endorsed more chronic illnesses on the HSQ than did controls (Haley. 1986). Caregivers did not differ from controls on the number of physical symptoms reported via the PILL. Health care utilization, (a variable not being analyzed in this study) was consistently higher for Alzheimer caregivers in the Haley (1986) study, with caregivers reporting a greater number of physician visits and prescription medications, than controls. Haley (1986) notes, "it is not clear from the health data whether caregivers are in objectively poorer health than controls; or whether they (caregivers) are more subjectively concerned about their health" (p. 23). Regardless of the mechanism, the health endpoints of poorer subjective/objective health, and increased health utilization, contribute to the growing "hidden" expenditures that may be attributed to the caregiving experience (Haley, 1986).

George and Gwyther (1986) compared Alzheimer caregivers' health (spouses) to the health of adult child caregivers and other family caregivers, via two measures: 1. number of doctors visits and 2. self-rated health. Results show spousal caregivers report more doctors visits and poorer self-rated health then the other two groups, even when age is statistically controlled (George and Gwyther, 1986).

Charlesworth et al. (1983) found that only 9% of the total study sample (not exclusively Alzheimer caregivers) felt that their ill health had been directly caused by their caring responsibilities, and 13% reported that caring had possibly worsened already poor health. The review of the concept 'perceived health status', is presented next (out-of-order) to preserve the continuity of the health theme in reviewing the literature.

Perceived Health Status

The concept, 'perceived health status' is represented in the study by the variable, 'caregiver perceived health status'. As the name implies, caregiver perceived health status is defined as a self-rated health appraisal (excellent, good fair, poor) reported by the caregiver. Perceived health status is a common method of assessing Alzheimer caregiver health in the literature (George and Gwyther, 1986; Haley, 1986; Pratt et al. 1987; Pratt et al. 1985).

In the study by George and Gwyther (1986), the Alzheimer caregiver sample was grouped according to caregiver/patient family relation and then values of self-rated health were compared among the different caregiver groups. Spousal caregivers reported significantly poorer perceived health than adult child, or other relative caregivers (George and Gwyther, 1986).

Haley (1986) compared primary Alzheimer caregivers to a matched control sample, on the variable of perceived health status, and found caregivers rate their health status poorer than controls. Admittedly, some caregivers may tend to focus on medical problems as one of the few ways of receiving a sanctioned relief from caregiving responsibilities. Nevertheless, Haley (1986) collected additional clinical data documenting that some of the sample caregivers had actually experienced major health problems since the advent of caregiving.

Perceived health status was used in the two Pratt et al. studies as a measure of caregiver health. Pratt et al. (1985), focused on identifying coping strategies used by Alzheimer caregivers and the relationship of these strategies to the caregiver's subjective sense of burden. Caregiver burden levels were found to be inversely related to caregiver perceived health status. Higher perceived health, equals lower burden score (Pratt et al. 1985).

The Pratt et al. (1987) study, focused on investigating Alzheimer caregiver health, burden and coping strategies, as a function of patient residence (community dwelling or institutionalized). Again, in this study, caregiver health was measured via the self-rated 4 point scale of excellent, good, fair, and poor. Results show caregiver burden scores inversely related to perceived health status among caregivers to community dwelling patients and institutionalized patients. The higher the caregivers' perceived health, the lower the burden score (Pratt et al. 1987). Caregivers' health status prior to caregiving was not significantly related to the patient's residence. However, caregivers' current health status was significantly related to patient residence, with caregivers to institutionalized patients significantly more likely to rate their current health status as "fair" or "poor" (Pratt et al. 1987). Caregivers to institutionalized relatives were also significantly more likely to report that caregiving had had a great negative affect upon their health status (Pratt et al. 1987). More importantly, Pratt et al. (1987) found that none of the coping strategies investigated in the 1987 study buffered the negative impact of caregiving upon caregiver physical health status. Use of positive psychological strategies (e.g., confidence, reframing) and social support were not related to the caregivers' perceived level of current health (Pratt et al. 1987).

No studies were found in which caregiver health (objective measure) or caregiver perceived health (subjective measure) were investigated in relation to caregiver self-care practices. Pratt et al. (1987) advises future researchers to further investigate the relationship of coping strategies to caregiver health status because health status is clearly related to the caregiver's ability to provide continuing care in the community. The advice of Pratt et al. (1987) is equally relevant to the investigation of self-care habits and caregiver health.

Psychological Characteristic

The concept, 'psychological characteristic' in this study, corresponds with the study variable, 'caregiver depression'. Research and literature pertinent to the study variable, 'caregiver depression' are presented in this section.

"For many caregivers, the attempt to provide care for an Alzheimer patient sets in motion a cycle of isolation, self-neglect, sadness, frustration and guilt" (Barnes et al. 1981, p.84). Investigations of the phenomena of caregiver depression represent an attempt to break the aforementioned cycle. One of the earliest study's of depression among Alzheimer caregivers was by Rabins, Mace and Lucas (1982), who reported 87% of the caregivers in a sample of 55 families reported chronic fatigue, anger, and depression. Goldman and Luchins (1984) presented a descriptive account of three Alzheimer caregivers', requiring hospitalization due to the stress of caregiving. Goldman and Luchins (1984) noted, "Because we were unable to find previous reports of this particular phenomenon, we felt it worthwhile to describe these cases" (p. 1467). From 1984 to the present, five additional studies were located in the literature, pertaining to caregiver depression (George and Gwyther, 1984; Gilhooly, 1985; Haley, 1986; Kahan et al. 1985; Pagel et al. 1985; Poulshock and Deimling, 1984). Each of the aforementioned researchers approached the topic of caregiver depression in a unique way. Therefore, the articles are reviewed individually.

George and Gwyther (1984) investigated cross-sectional data on Alzheimer caregiver well-being, and found the dimensions of mental health and social activity most adversely affected as a result of caregiving. Furthermore, George and Gwyther (1984) report spousal caregivers and other caregivers who reside with the patient report: the highest number of stress symptoms, the lowest ratios of positive to negative affect and the lowest levels of life satisfaction. In the George and Gwyther (1984) study, mental health was measured using three indicators: a checklist of psychosomatic stress symptoms, the Affect Balance Scale (measures the ratio of positive to negative affect within the past few weeks), and a single-item life satisfaction measure.

While not the primary focus of their study, Poulshock and Deimling (1984) found the caregiver's level of depression (measured by the Zung Depression Scale) to be reflected in a modest but persistent way in other measures of caregiving burden and impact. Poulshock and Deimling (1984) advise other researchers not to overlook caregiver depression, as an antecedent or intervening variable, especially when caregivers self-report survey data.

Gilhooly (1984) used the OARS Multidimensional Functional Assessment Questionnaire's, 'mental health scale' to measure the psychological well-being of caregivers to demented elderly. The assumption made by Gilhooly (1984) was that the impact of caring for a demented relative would be negative and result in poor mental health for the caregiver. Only marginal support was reported for the aforementioned assumption, with mental health ratings for caregivers ranging from good to mildly impaired, with no evidence of serious psychiatric disorders (Gilhooly, 1984). Limitations of the Gilhooly (1984) study include: cross-sectional analysis and lack of a control group for comparison.

In a controlled study, Kahan et al. (1985), analyzed Alzheimer caregiver depression by collecting pre and post intervention data using the Zung Self-Rating Depression Scale. The intervention included a specifically designed group support program for relatives of patients with Alzheimer's disease and related disorders. The group program included educational/supportive activities and used basic principles of the cognitive-behavioral approach. There was no significant difference between mean Zung scores for the experimental or control groups before treatment (Kahan et al. 1985). However, in the post-treatment evaluation, a higher proportion of experimental group subjects showed improvement and fewer deteriorated (than control subjects) on mean Zung score. Caregivers who showed the most improvement in their levels of depression, were also the individuals who evidenced the greatest gains in acquiring new knowledge about Alzheimer's disease, as a result of the support group intervention (Kahan et al. 1985). The results of the Kahan et al. (1985) study, indicate caregiver depression may be lessened by an intervention that offers practical knowledge about Alzheimer's disease, within a supportive environment where the caregiver can ask questions and discuss individual problems.

Haley (1986) compared Alzheimer caregivers' with a matched, non-caregiving, control group. Haley (1986) found the caregivers' subjective appraisals of their patients' problems were much more closely related to problems with caregiver depression than the objective severity of patient problems. Caregivers who used logical analysis and problem-solving mechanisms more frequently, showed lower levels of depression and higher life satisfaction (Haley, 1986). To measure caregiver depression, Haley (1986) used the Beck Depression Inventory (BDI).

Spousal Alzheimer caregivers were used in a study by Pagel et al. (1985) to test predictions derived from the reformulated learned helplessness depression model. The study was involved and complex, however, the gist involved the finding that caregivers' who at initial interview saw their patient's (spouse's) behavior as out of control and blamed themselves, had more depression at the follow-up interview than was predictable from their initial interview depression score alone (Pagel et al. 1985). To assess depression in the Pagel et al. (1985) study, a tool was derived from a principal components analysis of: the Beck Depression Scale, and the depression scale of the Symptom Checklist-90 (SCL-90).

In sum, many aspects of caregiver depression have been investigated and reported on in the literature. What is currently missing and to be provided via this study, is an analysis of the relationship between caregiver depression and caregiver self-care practices.

Situational Factor

The concept, 'situational factor' corresponds to the study variable, 'impact of caregiving on the caregiver's schedule'. The variable was previously defined, for the purposes of this study, as the degree to which caregiving alters the caregiver's normal daily schedule (Given and Collins, 1987). No prior research was found linking caregiver self-care to a measure of caregiver schedule interruptions. Nevertheless, the degree of schedule change imposed on Alzheimer caregivers (as a result of caregiving) has received previous attention in the literature.

Barnes et al. (1981) investigated the effectiveness of support groups for Alzheimer caregivers. A major problem, reported by all subjects in the Barnes et al. (1981) study, was the great amount of time required to care for even a mildly impaired Alzheimer patient. "Spouses spent so much time looking after the patient that they seemed to identify themselves with the patient and often lost sight of their own personal needs and interests" (Barnes et al. 1981, p. 82). As part of the support group program in the Barnes et al. (1981) study, Alzheimer caregivers were encouraged to take better care of themselves and to find ways to get out of the house to pursue personal interests and activities. As a result of the support group experience, "caregivers began to understand that occasional attention to their own needs, improved their mental well-being, and brought new energy, and a more positive outlook to the task of caring for the patient" (Barnes et al. 1981, p. 84).

In studying the role of coping behaviors for primary caregivers of Alzheimer's patients, Scott el al. (1987) found the two most common coping strategies used were: a change in the amount of time spent with the patient and a modification in the caregivers' use of free time. Caregivers reported the stress of caregiving to be less when "time away" was available to participate in activities outside of caregiving (Scott et al. 1987).

To provide a basis for Alzheimer education and support group programs, Clark and Rakowski (1983) reviewed the existing literature and identified points of consensus regarding major tasks faced by caregivers. The top two tasks in the category, "Personal Tasks Faced by Family Caregivers" were, "to compensate for emotional drain from constant responsibility" and "to compensate for, or recover personal time" (Clark and Rakowski, 1983, p. 638). Both of the aforementioned tasks were marked with an asterisk, denoting a task which appeared to be especially stressful or difficult for the caregivers (Clark and Rakowski, 1983).

Caserta et al. (1987) looked at the need for and use of community services by Alzheimer caregivers. Although the service needs reported by caregivers varied, some type of respite, day-care, or in-home care, accounted for 71% of the service needs reported (Caserta et al. 1987). Similar to responses for needed services, the most frequently utilized service was respite, accounting for 63% of the service utilization reported (Caserta et al. 1987). In an indirect fashion, the results of the Caserta et al. (1987) study, address the issue of the impact of caregiving on the caregivers' schedule by highlighting the need and use of services providing "time-out" for the caregiver.

In an effort to more specifically define the concept of caregiver burden, Montgomery et al. (1985) researched the subjective and objective components of caregiver burden. The factors that were found to be associated with subjective burden (e.g., age, income) were characteristics of the caregiver that could not be easily altered. In contrast, objective burden, was found to be related to tasks of caregiving. Tasks that confined the caregiver in terms of time schedule and/or geographic location contributed most to the level of objective burden (Montgomery et al. 1985).

Clearly, the impact of caregiving on the caregivers' time and schedule is being investigated and reported on in the literature. To augment the existing research, this study will provide insight into how impositions of caregiving (on the caregivers' schedule) are related to the caregivers' self-care practices.

Interpersonal Influence

The concept, 'interpersonal influence' is associated with the study variable, 'social interaction of the caregiver'. As presented earlier in the study, social interaction of the caregiver is defined as the quantity and types of contacts caregivers have with others in their environment (Given and Collins, 1987). How caregiver social isolation or social connectedness relates to caregiver self-care has not previously been reported on. However, caregiver social interaction has been linked to other aspects of caregiving (George and Gwyther, 1986; Haley, 1986; Johnson and Catalano, 1983; Zarit et al. 1980; Zarit and Zarit, 1982). The aforementioned studies, speak to caregiver social isolation increasing with deterioration of the Alzheimer patient, and also mediating the effect social support has on caregiver burden.

George and Gwyther (1986) examined social activity as one of four dimensions of well-being of Alzheimer caregivers. Comparing random community samples to Alzheimer caregivers, George and Gwyther (1986) found caregivers report substantially lower levels of social activity than the comparison random community samples. Due to the cross-sectional nature of the data, it is impossible to determine whether the perception that one is lacking social interaction leads to decrements in well-being, or whether decreased well-being leads to the perception that more social support is needed (George and Gwyther, 1986). Nevertheless, the correlations between reported adequacy of social interaction and caregiver well-being are strong and pervade all four dimensions of well-being measured in the study (George and Gwyther, 1986).

Haley (1986), compared Alzheimer caregivers with a non-caregiving, age matched, control sample to assess the effects of caregiving on the caregivers' social functioning. Caregivers and controls had similar numbers of: social network contacts and activities with families, however, caregivers were significantly less satisfied with their networks than controls (Haley, 1986). Haley (1986), explained the caregivers dissatisfaction with adequacy of their social network, as a function of the caregivers' greatly increased need. In the second part of Haley's (1986) study, caregiver social support variables were assessed for their correlation with subsequent caregiver depression, life satisfaction and health. The pattern of correlations showed that social supports serve a positive function in enhancing caregivers' perceived quality of life and decreasing caregiver depression. In addition, social support variables were closely linked to caregivers' subjective ratings of health, with socially isolated, inactive, caregivers reporting poorer health (Haley, 1986).

In the often cited study by Zarit et al. (1980), factors contributing to feelings of burden among Alzheimer caregivers were studied. The results of Zarit et al. (1980) include the now well documented finding that caregiver burden is not associated with the degree of behavior problems exhibited by the patient. Zarit et al. (1980) also reported social support, in the form of sheer quantity of visits from other family members and friends, was directly associated with the degree of burden caregivers' reported (more visits = less burden).

In opposition to the reported association between caregiver social interaction/support and better caregiver functioning, is a study by Pratt et al. (1985). Pratt et al. (1985) reported caregiver burden scores were not related to: presence of one or more confidant relationships, membership in a support group, or calling upon friends/neighbors. Surprised by the results, Pratt et al. (1985) warns the reader to interpret the burden/social support findings cautiously. The authors of the Pratt et al. (1985) study note the unexpected results may be a function of: "the sample, the nature of the particular support groups, the degree of respondent's participation in the support groups, and/or some other factor" (p. 31).

In sum, adequate social interaction with family and friends, appears to mediate the impact of Alzheimer related problems on the caregivers. The implication is: interventions to improve the social "connectedness" of the caregiver may relieve some of the physical and emotional burden experienced by the caregiver.

Behavioral Support

The study concept, 'behavioral support' corresponds with the study variable, 'amount of assistance from family and friends'. Caregiver amount of assistance from family and friends was defined earlier in the study as, the assistance family and friends provide in performing tasks for the caregiver (Given and Collins, 1987). Thus, behavioral support, can be thought of as tangible support, opposed to social support, which is more an intangible type of support.

The variable 'amount of assistance from family and friends' has been operationalized in various ways and linked to: desire to institutionalize patient, caregiver morale and mental health, caregiver burden or strain, and caregiver coping (Gilhooly, 1984; Goldstein et al. 1981; Montgomery et al. 1985; Morycz, 1985; Scott et al. 1987; Scott et al. 1986; Zarit and Zarit, 1982). No previous studies were found in which relationships between caregiver self-care and the amount of practical support provided to the caregiver were investigated.

In two studies by Zarit (Zarit et al, 1980; Zarit, 1982) it was reported that caregivers of impaired elderly feel most burdened when they perceive they do not have the support of family and friends. Gilhooly (1984) found similar results, and reported it was the caregivers' satisfaction with help received, rather than the amount of help received, that correlated significantly with caregiver morale. It appears the Zarit and Gilhooly studies' have tapped a common theme of, caregivers' perception of practical assistance explaining more of the variance in caregiver burden and morale, than the amount of practical assistance alone.

Scott et al. (1986) examined the instrumental (tangible) and social-emotional (intangible) support provided by families to the primary caregivers of Alzheimer's patients. It was hypothesized and subsequently confirmed in the Scott et al. (1986) study, that the more adequate the support, the less sense of burden and better coping effectiveness of the caregiver. The type of assistance reported by caregivers to be most appreciated included: having persons stay with the patient so that the caregiver could get out of the house for errands, social activities and rest (Scott et al. 1986).

In a more recent article by Scott et al. (1987), the use and effectiveness of eleven coping strategies was investigated using a sample of Alzheimer caregivers. The coping strategy accounting for the largest reduction in caregiver stress was, solicitation of outside aid (Scott et al. 1987). Seeking outside aid, was also one of three coping strategies reported as being used most frequently by the Alzheimer caregivers' sample to reduce stress (Scott et al. 1987). The Scott et al. (1987) study did not delineate what type of outside assistance was sought most often. Nevertheless, the authors encouraged health care professionals to aid the caregiver in developing a referral network to coordinate caregiving responsibilities (Scott et al. 1987).

In an effort to more precisely define the construct 'caregiver burden', Montgomery et al. (1985) proposed the establishment of subjective and objective components of caregiver burden. Correlates of objective burden were found to include: the type of caregiving tasks performed, (especially those tasks confining the caregiver in terms of time schedule and/or geographic location) and the presence of other family members to assist with caregiving (Montgomery et al. 1985). The aforementioned data is in agreement with the contention that interventions aimed at freeing the caregiver temporarily from his or her caregiving duties, are effective in reducing the level of objective burden.

The desire of an Alzheimer caregiver to institutionalize the patient in their charge was found by Morycz (1985) to be greater when the caregiver experienced increased strain or burden. In turn, the strain or burden perceived by the caregiver was found to be related to the availability of someone to stay with the patient, and the existence of any other back-up help to relieve the primary caregiver as needed (Morycz, 1985). The relationship of availability of assistance and lower caregiver strain, was not observed among male caregivers and black caregivers. Morycz (1985) notes that male caregivers seek out and utilize assistance or services more than female caregivers, and this may account for males perceiving lower levels of caregiver strain. Haveven (1980) observed that the kinship network of black families has traditionally been quite powerful, and black families rely on extended kin more heavily than white families in times of strain. Therefore, black caregivers may utilize available supports more often resulting in lower strain for the black caregiver.

In summary, it appears behavioral support in the form of respite for the caregiver, is most desired by caregivers and most effective in alleviating caregiver strain or burden. Unfortunately, the benefits of behavioral support are not achieved simply by providing respite care. The caregiver's perceived satisfaction with assistance provided must be considered as a factor in determining the overall value of the support effort.

A Nursing Perspective

In a selected literature review by Goodman (1986) of British research on the informal carer, it was reported that there is a limited amount of research which reflects a nursing perspective. Similarly, Robinson (1986) found it interesting that other disciplines were identifying the need for nursing's role in caregiving, yet, nurses were not writing about caregiving.

Of the caregiving research reviewed for this study, the majority (of literature) represents the disciplines of: social gerontology, social work, psychology, and medicine. Admittedly, the review of the literature presented for this study is not inclusive of all current caregiver literature and very recent works may not be represented. Reflections, a quarterly publication by Sigma Theta Tau International, (honor society of nursing) lists descriptive synopses of recent Doctoral dissertations. In a recent issue of Reflections, (Chestnut, 1987) a number of dissertations were listed involving some aspect of caring for the Alzheimer patient. These dissertations were too recent to be avaiable for this literature review. However, nursing dissertations are evidence of a burgeoning research base reflecting nursing's role in the arena of caregiving.

Nurses in advanced practice are well suited for assuming leadership positions in the organization and delivery of health care for caregivers and Alzheimer patients alike. The role of the clinical nurse specialist will be discussed in detail in Chapter Six. The purpose of this section, was to mention the conspicuous lack of research from the nursing sector, pertaining to Alzheimer patients and their caregiving companions. Fortunately, the future looks promising, as nurses become more involved in an issue (caregiving) ripe for nursing intervention.

"Status" of Current Study in Relation to Prior Alzheimer Caregiver Research

This section contains a brief discussion of how the current study "fits" into the larger body of Alzheimer caregiver literature. In regard to subject matter, this research is unique, as no previous studies were found in which caregiver self-care practices were investigated as the primary research objective. Considering the previously reviewed literature, Alzheimer caregiver self-care practices, were sometimes indirectly or tangentially explored as a result of another variable related to self-care being analyzed (i.e., caregiver well-being or caregiver health). Nevertheless, this study represents an initial effort to identify caregiver self-care behaviors and variables which may impact self-care practices in a negative or positive manner.

Methodologically speaking, this study involves procedure that have been criticized by other researchers. Jenkins et al. (1985) cite several methodological limitations commonly found in the Alzheimer caregiver literature:

> - relatively small, homogeneous sample sizes
> - cross-sectional studies limited by the incumbent weakness of the design
> - lack of longitudinal studies
> - operational definitions of variables inconsistently applied and defined differently in virtually every study
> - lack of replication studies
> - researchers reaching their study population via the subjects' (caregivers') pre-existing contact with formal services (i.e., support groups, ADRDA chapters, physician offices)
>
> (Jenkins et al. 1985, p. 45)

The current study is "guilty" of many of the aforementioned methods and procedures. However, because of the lack of previous research pertaining to caregiver self-care, some of the criticized methods and procedures are difficult to avoid. More importantly, the aforementioned undesirable procedures and methodologies, are criticized for contributing to the difficulty in comparing Alzheimer caregiver research and the absence of consistent findings in measuring the consequences of caregiving.

Lastly, while many researchers have succeeded in calling attention to the predicaments and dilemmas Alzheimer caregivers face in maintaining the Alzheimer patient. Most of the solutions have yet to be provided. The majority of the studies reviewed, made recommendations for more service provision for carers, when the study's main work had only described the needs and not tested what the best solutions could be. This study is not an intervention study. However, any recommendations put forth in this study must be regarded as tentative, pending empirical evidence to support the proposed recommendation. In addition, when testing any of the various innovative, intervention strategies suggested in the literature, the researcher must account for the needs of both the caregiver and patient, prior to endorsing any one particular intervention.

Summary

The content of Chapter Three has included: a brief review of Pender's (1987) health promotion model; a review of the research and literature pertinent to the study concepts and associated variable(s); a critique of the literature from a nursing perspective and lastly an overview of how this study "fits" into the larger body of Alzheimer caregiver literature. The focus in Chapter Four, is a comprehensive outline of the study methodology and planned procedures.

CHAPTER IV

Methodology and Procedures

Overview

A survey design was used to retrospectively identify the self-care practices of primary caregivers to Alzheimer's patients and to describe the relationship between selected variables and caregiver self-care. This secondary analysis is based on data collected as part of a federally funded Alzheimer's caregiver research project, The Impact of Alzheimer's Disease on Family Caregivers, grant #1R01-MH41766-01, conducted by C.W. Given and B. Given (1986) co-principal investigators. The project, funded by The National Institute of Mental Health, was designed to develop and test instruments for use with primary caregivers to Alzheimer's patients. The funded project was completed in 1988 with data collected from one hundred twenty Alzheimer's caregivers. Participants (caregivers) were solicited from numerous health and social agencies located in major metropolitan and surrounding areas of lower Michigan.

All the data collected at the intake interviews of the original (funded) project, were used for the cross-sectional analysis in this study. Therefore, the descriptions of: population, sample, instrument development, data collection procedures, and human rights protection, are identical to those used in the original research project, unless stated otherwise.

Research Questions

Question 1. What are the reported self-care practices of a sample of primary (family) caregivers to Alzheimer's patients?

Question 2. What relationship do selected independent variables have with the caregiver's performance of self-care. Specifically: how are the following independent variables related to Alzheimer's caregivers' self-care?

-caregiver age
-caregiver sex
-caregiver marital status
-duration of caregiving
-caregiver education
-caregiver employment status
-caregiver relation to Alzheimer's patient
-caregiver health
-caregiver perceived health
-caregiver depression
-caregiver social interaction
-caregiver amount of assistance from family/friends
-impact of caregiving on caregiver's schedule

Population

A population of primary (family) caregivers of Alzheimer's patients was identified from community agencies, home care agencies, day care centers, physician practices, and Alzheimer's support groups in the lower Michigan area. Criteria for caregiver participation included:

1) caregivers must identify themselves as the primary person responsible for the care of the patient in their charge;

2) the patient must be 55 years of age or older;

3) the patient must be living in the home of the caregiver;

4) the caregiver must be related to the patient;

> 5) according to the caregiver, the patient must have been diagnosed as having Alzheimer's Disease or a related dementia, and respond positively to two questions from a behavior scale developed for the study by the research team members.
> (Given and Given, 1986, p.68)

Ideally, the target population to whom the results of this study could reasonably be generalized, includes primary (family) caregivers to elderly Alzheimer's patients. However, because the accessible population is not a random selection of the ideal target population, study results cannot be generalized. Strictly speaking, the findings from this research can be generalized only to the study sample.

Sample

The study sample is described as the sample existing in Phase I of the original study. The initial, intake interview data is used for the secondary analysis of the variables in this study. Caregivers fulfilling the selection criteria were sent letters seeking their willingness to participate in the study. The letter included the description and purpose of the study, its potential benefits, and the length of time required for participation. Subjects willing to participate were asked to return a postcard; a name and telephone number were also provided for those desiring additional information. Follow-up on all letters and postcards was done via telephone by an interviewer. During this time, the study was again described and questions answered. One hundred twenty caregivers, ages 28 to 85, agreed to participate and complete the intake interview.

It is the aforementioned one hundred twenty caregivers, and the data they reported on the intake interview of the original study, which compose the sample for this research study. Because the sample was voluntary in nature, and not randomly selected, the results of the study can only be generalized to the sample subjects.

The Funded Project

As mentioned earlier, the original (funded) study: The Impact of Alzheimer's Disease on Family Caregivers, included two phases. Information collected in the Phase I intake interview was done using the Alzheimer's Family Care Study Questionnaire. Phase II will not be described in-depth here. Briefly, phases II of the original study, involved a re-test of the same instruments (composing the Family Care Study Questionnaire) with a one month follow-up for stability. Those desiring additional information about the original study's methodology and procedures are referred to Given and Given, (1986).

Operationalization of the Study Variables

Self-care

Caregiver self-care was defined previously as, generic (not gender specific) activities, performed by caregivers in the areas of: nutrition, disease prevention, exercise, and stress reduction/relaxation, to improve or maintain good health. As the dependent variable in the investigation, caregiver self-care is the outcome variable of interest.

To obtain a measure of caregiver self-care, and answer the first research question in this study, the "self-care practices" section of the Alzheimer's Family Care Study Questionnaire was used. The first 23 questions in this instrument, "self-care practices" query the caregivers on common self-care behavior and practices. Responses include: 1) "never do this"; 2) "do this occasionally"; 3) "do this regularly". Questions 24 and 25 provide a different response pattern where the caregiver is asked to report smoking behavior and alcohol intake by quantity.

The self-care portion of the Alzheimer's Family Care Study Questionnaire, is not yet an established instrument for measuring self-care practices/behaviors. It (the instrument) was developed by Given and Collins (1987), for the purpose of their study. As explained later in this Chapter, a factor analysis was done on the original 25 self-care questionnaire items. The resulting smaller set of self-care dimensions is used in the current study as the measure of caregiver self-care.

Demographics

The independent variables in this study can be broken down into demographic and non-demographic variables. The demographic variables include caregiver: age, sex, marital status, duration of caregiving, education, employment status, and relation to the Alzheimer's patient. All of the aforementioned demographic variables were examined using the original items on the Alzheimer's Family Care Study Questionnaire. The operational definitions of the demographic variables are presented in the following table format.

Table 4.1 Operational Definitions of the Demographic Variables

Demographic Variable	Operational Definition
caregiver age	reported date of birth -month/day/year
caregiver sex	reported gender -male/female
caregiver marital status	reported: -never married, -widowed, -separated, -divorced
caregiver duration of caregiving	-reported number of years caregiver has been helping
caregiver education	reported: -grade school or less, -some high school, -high school graduate, -some college tech training, -college grad, -graduate or professional degree
caregiver employment status	reported: -employed -unemployed
caregiver relation to Alzheimer's patient	reported: -spouse -child -daughter/son in-law -brother/sister in-law

Health

Caregiver health was defined earlier as: the number of chronic diseases or physical problems the caregiver experiences, and the degree to which these diseases or problems negatively impact the caregiver's life-style. In this study, the variable caregiver health, is designated as an objective assessment of the caregiver's health.

The variable, caregiver health, was measured via survey item two in the "physical health: caregiver" section of the Alzheimer's Family Care Study Questionnaire. Item two, in the caregiver physical health section, provides data on 15 diseases or physical conditions. The caregiver is asked to respond, yes\no to the presence of the disease or condition and then to report how much difficulty the particular problem causes the caregiver: 1) "no difficulty", 2) "some difficulty", 3) "a great deal of difficulty".

Perceived Health

Caregiver perceived health status was earlier defined as the rating or condition a person selects to describe his/her current health status. In this study, the variable, caregiver perceived health, is designated as a subjective assessment of the caregiver's health status. The variable, caregiver perceived health, was measured via the standard single-item question, "How would you rate you overall physical health at the present time?: excellent, good, fair, poor" (Given and Collins, 1987).

Depression

Caregiver depression was defined previously as, "an ego state in which the individual's emotional expression of helplessness and powerlessness occurs; characterized by loss of self-esteem in reaction to: the wish to be worthy, loved and appreciated, the wish to be good, loving and unaggressive and the wish to be strong superior and secure" (Burgess and Lazare, 1976, p. 220). In this study, caregiver depression was measured using the 20-item Epidemiologic Studies Depression Scale (CESD-20). The twenty items composing the CESD, reflect the definition of the variable, caregiver depression, as defined in this study.

Impact of Caregiving on Schedule

The impact of caregiving on the caregiver's schedule was previously defined as: the degree to which caregiving alters the caregiver's normal daily schedule (Given and Collins, 1987). The loss of "routine", or the inability to reliable schedule, (due to caregiving responsibilities) presumably may effect the caregiver's ability to carry out self-care practices/behaviors.

To measure the impact of caregiving on the caregiver's schedule, five items from the Alzheimer's Family Care Study Questionnaire were used. Caregivers were asked to respond: "strongly agree", "agree", "neither agree nor disagree", "disagree", "strongly disagree", to five items pertinent to the impact of caregiving on their schedule.

Social Interaction

Caregiver social interaction was defined earlier, as the quantity and type of contacts caregivers have with others in their environment (Given and Collins, 1987). In this study, caregiver social interaction is designated as a measure of caregiver social "connectedness" or isolation.

Social interaction of the caregiver was measured using six items from the Social Resources Scale, developed by the Rand Corporation. Caregivers are asked to report how often they: get together with friends/relatives, have friends over to their house, visited with friends at their (the friends') home, talk on the phone with friends, write a letter to a relative/friend, and attend religious services (Given and Collins, 1987). To answer the aforementioned six items, caregivers may respond: "every day", "several days a week", "about once a week", "2-3 times in a month", "once in the past month", "not at all in the past month" (Given and Collins, 1987). As mentioned by Given and Collins (1987), the Rand Corporation Social Resources Scale represents one of the few recent attempts to scale and quantify, in a systematic fashion, the types of contacts individuals have with others in their environments.

Assistance from Family and Friends

Caregiver amount of assistance from family and friends, was defined previously as the assistance family and friends provide in performing tasks for the caregiver (Given and Collins, 1987). In this study, the tasks family and friends may assist with are defined as: routine chores, heavy cleaning, transportation, making meals, legal/money matters, and watching the Alzheimer's patient so the caregiver may have time away.

To measure the amount of practical support the caregivers receive from family and friends, caregivers were asked to report via the Alzheimer's Family Care Study Questionnaire: "How many times in the past three months have family or friends . . . checked regularly on you, helped with routine chores, helped with heavy cleaning, legal or money matters, transportation, made meals for you, or taken care of your relative so you could get away?" (Given and Collins, 1987). The numerical values reported on the aforementioned seven questionnaire items, compose the measure of assistance from family and friends, used in this study.

Development of Instruments

The instruments in this study were drawn from those designed for, The Impact of Alzheimer's Disease on Family Caregivers (Given and Given, 1986). The majority of questionnaire items composing the instruments used in this study, came from the Alzheimer's Family Care Study Questionnaire, used to collect the data for the original study by Given and Given (1986).

All of the scales or instruments used to operationalize the variables in this study were used in their original form, except, the caregiver self-care practices/behaviors measure. In the original study, The Impact of Alzheimer's Disease on Family Caregivers, caregiver self-care was assessed via fifty self-care questionnaire items collated by the principal co-investigators and their staff (Given and Given, 1986). In this study, the variable caregiver self-care was assessed using five common dimensions identified by conducting an exploratory factor analysis on self-care items one through twenty five (from the original Alzheimer's Family Care Study Questionnaire). The factor analysis procedure seemed to result in five self-care areas representing the common characteristics or underlying dimensions of the original twenty-five self-care questions. The resulting five dimensions of caregiver self-care were labeled: Physical-care, Time-care, Sleep-care, Social-care, and Diet-care. These aforementioned labels were chosen because the labels are descriptive of the questionnaire item clusters resulting from the factor analysis.

Physical-care

The dimension, Physical-care, includes three questionnaire items:

-exercise 15-30 minutes three times per week
-maintain ideal body weight
-in a normal day walk a minimum of one mile

Time-care

The dimension, Time-care, includes five questionnaire items:

-leisure activity for fitness
-sleep 6-8 hours per night
-sleep easily without medication
-take time for myself daily
-go out with friends daily

Sleep-care

The dimension, Sleep-care, includes three questionnaire items:

-sleep 6-8 hours per night
-have uninterrupted sleep
-sleep easily without medication

Social-care

The dimension, Social-care, includes three questionnaire items:

-leisure time for fitness
-take time for myself daily
-go out with friends daily

Diet-care

The dimension, Diet-care, includes three questionnaire items:

-limit fat and cholestrol
-limit refined sugar
-limit amount of salt

Therefore, caregiver self-care, is the only variable that had not yet been scaled in the original study. The exploratory factor analysis performed in this study operationalized the self-care variable for the purpose of this research.

Scoring

The scoring for each of the operationalized variables in the study is briefly described in this section.

Self-care

The self-care items were scored by assigning a point value ranging from one to three for each of the three possible responses. Caregivers were asked to report how frequently they performed specific self-care practices/behaviors: "1 = never do this", "2 = do this occasionally", "3 = do this regularly".

Demographics

A table format is used to present the seven demographic variables, and how each variable was scored.

Table 4.2 Scoring of the Demographic Variables

Demographic Variable	Scoring Process
caregiver age	no scoring involved reported as caregiver's numerical age, calculated from date of birth
caregiver sex	1 = male 2 = female
caregiver marital status	1 = single, never married 2 = married 3 = widowed 4 = separated 5 = divorced 6 = other
caregiver's duration of caregiving	no scoring involved, reported as number of years caregiver has been helping
caregiver education	1 = grade school or less 2 = some high school 3 = high school graduate 4 = some college technical training 5 = college grad 6 = graduate or professional degree
caregiver employment status	1 = yes 2 = no

caregiver relation to Alzheimer's patient	1 = spouse 2 = child (daughter/son) 3 = daughter/son (in-law) 4 = brother/sister (in-law) 5 = other

Health

The variable, caregiver health, was scored first, by asking the caregiver to report the presence or absence of fifteen diseases or conditions: "1 = yes, 2 = no". Next, the caregiver was asked to report how much difficulty each particular disease or condition caused them: "1 = no difficulty", "2 = some difficulty", "3 = great deal of difficulty". The numerical values for the designated responses provided a means to evaluate the caregivers in relation to health problems and the severity of the health problem.

Perceived Health

Scoring of the caregiver perceived health variable, was accomplished by assigning a numerical value to the four possible responses. When asked to rate their current health status, caregivers could respond: "1 = excellent", "2 = good", "3 = fair", "4 = poor". As mentioned in Chapter One, the aforementioned perceived health status scale, has been shown to correlate highly with physician ratings of health, and to be a better predictor of subsequent mortality than objective health ratings (Haley, 1986).

Depression

The CESD depression scale used to measure caregiver depression, was scored by assigning numerical values to the four possible responses: "1 = rarely/none of the time", "2 = some of the time", "3 = most of the time", "4 = almost all of the time". Four of the twenty items composing the CESD scale are stated negatively, and scores must be reflected. For these four items, (survey items 14, 18, 22, 26) the response scale was numerically reversed to create consistency in scoring the items.

Impact of Caregiving on Schedule

The scale used to operationalize the variable, impact of caregiving on schedule, was composed of five items from the caregiving inventory section of the Alzheimer's Family Care Study Questionnaire. The five items were scored by assigning numerical values to the five likert type scale responses: "1 = strongly agree", "2 = agree", "3 = neither agree nor disagree", "4 = disagree", "5 = strongly disagree". A mean value was computed for each caregiver on the five survey item responses. Therefore, caregivers can be compared using the mean computed on the five "impact on schedule" survey items.

Social Interaction

The six survey items used to measure the variable, caregiver social interaction, were scored by assigning a numerical value to each possible response. For unknown reasons, the first item on the social resources scale (in the Alzheimer's Family Care Study Questionnaire) was scored differently than the other five. The first survey item had seven response choices and the others had six. In this study, the numerical values for all six survey items (from the original scale) were reversed, so that a high numerical score represented greater frequency of the particular social activity. Caregivers were asked to respond how often they engaged in specific social activities. For the first scale item, the choices were: "7 = everyday", "6 = several days a week", "5 = about once a week", "4 = 2 or 3 times a month", "3 = about once a month", "2 = 5-10 times a year", "1 = less than 5 times a year". For the other five scale items the choices were: "6 = everyday", "5 = several days a month", "4 = about once a week", "3 = 2-3 times in a month", "2 = once in past month", "1 = not at all in past month". The responses from all six survey items were summed to represent the caregivers "total" social interaction score.

Assistance from Family and Friends

The variable, amount of caregiver assistance provided by family/friends, was scored in a two-part fashion similar to the caregiver health variable. To begin, the caregiver was asked to report: 1 = yes, 2 = no, as to whether certain activities of assistance were provided by family/friends. Next, the caregiver was asked to report how often in the past three months, family or friends provided each designated assistance behavior. In sum, to measure caregiver assistance, the caregiver was queried on seven assistance behaviors and how often the behavior occurred in the past three months. Measuring assistance in the aforementioned manner, allowed a comparison of the designated assistance behaviors and which ones occurred most frequently.

Validity

Validity refers to the degree to which an instrument measures what it is intended and presumed to measure. The items in a scale are examined to ensure that: 1) they are all concerned with the construct under study; 2) that the whole range of the construct is covered by the items; 3) that no particular aspect of the construct is given undue weight (O'Muircheartaigh and Francis, 1981). The process to establish content validity involves subjective judgement and may best be delegated to a panel of experts (Polit and Hungler, 1983; O'Muircheartaigh and Francis, 1981).

The scales used in this study, were developed after a literature review, interviews with Alzheimer's caregivers, and the expert knowledge and judgement of the co-principal investigators and their research colleagues. Face validity is the most superficial examination of the validity of a scale and involves merely checking that all the items in the scale are dealing with some aspect of the construct under study. Face validity for the scales used in this study was based on the expert opinion of the co-principal investigators and colleagues.

A factor analysis was done as part of this study on, self-care survey items one through twenty-five. The data from the factor analysis can be used to suggest ways to revise the self-care instrument as to improve the measurement of the self-care construct. None of the other scales used in this study were subjected to additional tests of validity, other than the validity analyses carried out as part of the original study.

Reliability

The reliability of a measuring instrument is defined as, "the degree of consistency or dependability with which an instrument measures the attribute it is designed to measure" (Polit and Hungler, 1983, p. 385). All measurement scores are considered to be made up of two parts: a true score component and an error score component. A reliable measure is one that, "maximizes the true score component and minimizes the error component" (Polit and Hungler, 1983, p. 385).

There are a number of techniques which may be used to compute a reliability coefficient. In this study, the discussion of reliability is limited to the technique pertinent to this research. Internal consistency is one way of approaching the concept of reliability and is the approach used in this study. Internal consistency implies that all scale items are equivalent in terms of measuring the critical attribute. Coefficient alpha is the preferred method of estimating internal consistency. Coefficient alpha is preferred because, "it gives an estimate of the split-half correlation for all possible ways of dividing the measure into two halves" (Polit and Hungler, 1983, p. 391). The normal range of values for coefficient alpha is 0.00 to 1.00. The higher the alpha coefficient, the higher the degree of reliability (Polit and Hungler, 1983).

The psychometric properties (reliability, standard deviation, mean) of most of the scales used in this study, were investigated in Phase I of the original (funded) study, using a sample of one hundred eleven Alzheimer's caregivers. The scales used in the study are presented in table 4.3 with: Cronbach's alpha, standard deviation, mean (when available) for each scale.

The psychometric properties, (reliability, standard deviation, mean) of the five caregiver self-care dimensions resulting from the factor analysis, (performed as part of this study) are presented following Table 4.3 in Table 4.4. Data from the study sample (one hundred twenty caregivers) were used to analyze the reliability of the self-care measures.

Table 4.3

Summary table of Phase I testing, subject (n = 111).

Operationalized Variable	Reliability Cronbach's alpha	Standard Deviation	Mean
Caregiver Self-care	***** not tested in Phase I *****		
Demographics	** only frequencies reported in Phase I **		
Caregiver Health	not applicable	3.3	4.0
Caregiver Perceived Health	not applicable	.75	1.9
Caregiver Depression CESD-20	.88	.43	1.79

Operationalized Variable	Reliability Cronbach's alpha	Standard Deviation	Mean
Impact of caregiving on schedule	.86	.81	3.85
Caregiver social interaction	.68	1.8	4.1
Caregiver assistance from family/friends	not applicable	1.7	2.7

Scales with reliability values reported as, "not applicable" are scales not amenable to reliability analysis. For example, the "caregiver perceived health scale" and the "caregiver assistance from family/friends scale" are single variables so that measurement issues cannot be addressed.

Table 4.4
Summary table of self-care dimensions/factor analysis (n = 120).

Operationalized Variable	Reliability Cronbach's alpha	Standard Deviation	Mean
Physical-care	.51	1.8	6.2
Time-care	.74	2.7	13.6
Sleep-care	.64	1.5	7.2
Social-care	.64	1.7	6.5
Diet-care	.66	1.5	7.7

Reviewing the reliability values (Cronbach's alpha) in Tables 4.3 and 4.4, the alpha values range from a high of .88 to a low of .51. Because the alpha values in Table 4.3 are generally high and were not calculated as part of this immediate research, a discussion of the lower alpha values in Table 4.4 is presented. The alpha coefficients in Table 4.4, correspond with the five dimensions of the dependent variable 'self-care'. The dependent variable 'physical-care' had the lowest alpha (alpha = .51) and is composed of three divergent self-care questionnaire items. To improve the alpha value for 'physical-care' a greater number of more highly correlated questionnaire items pertinent to 'physical-care' must be utilized. The highest alpha value was achieved with dependent variable, 'time-care' (alpha = .74). 'Time-care' is composed of five questionnaire items grouped as a result of the factor analysis performed on the original twenty-five questionnaire items. The higher alpha achieved with 'time-care' may be due to the greater number of questionnaire items (five) included in this variable and the higher correlation among those five questionnaire items. The other three dependent variables: 'sleep-care', 'social-care', 'diet-care', had similar alpha values (alpha = .64, .64, .66) and were composed of three questionnaire items. Attempts to improve the alpha values of the aforementioned three scales/variables would likely require an increase in the questionnaire items included in the scale/variable and checking for high correlation among the questionnaire items included.

Data Collection Procedures

The data used in this study, was collected from one source: interviews with the Alzheimer's caregivers. Included in this section, is a description of the training and supervision of the interviewers and procedures for data collection using the Alzheimer's Family Care Study Questionnaire. Because this study involves only data collected at the initial intake interviews (of the original funded study) the discussion will be limited to the procedures of data collection up to the initial intake interviews only.

Caregivers fulfilling the selection criteria were sent letters seeking their willingness to participate in the study. Caregivers were asked to return the self-addressed postcard indicating their willingness to participate. Caregivers were then contacted by phone and scheduled for an intake interview. Initial intake interviews lasted approximately one and one-half hours. Caregivers were not fatigued by the time spent or the questions asked. "Indeed, they (caregivers) were anxious to tell 'their story' and share their perceptions with the interviewer" (Given and Collins, 1986).

The research interviewers included graduate students from Michigan State University College of Nursing, and trained lay interviewers. The interviewers received two days of instruction which included an overview of the research project, ethics of interviewing, and the responsibilities and techniques of interviewing. The research interviewers administered the survey items from the Alzheimer's Family Care Study Questionnaire to the caregiver. One hundred twenty caregivers completed the initial intake interview of Phase I. The data from the Phase I intake interviews, is the data on which this study is based.

Human Subjects Protection

The rights of the respondents were protected through adherence to standard criteria set forth by the Michigan State University Committee on Research Involving Human Subjects. All potential subjects were sent a letter describing the study and soliciting the participation of both the patient and the caregiver. The letter described the study and its benefits, assured participants of anonymity and confidentiality, and requested the caregiver return the enclosed self-addressed, stamped, postcard if interested in participating.

An interviewer initiated telephone contact with potential subjects who returned a postcard indicating a willingness to participate in the study. During the telephone conversation, the study was again described and questions answered. If the caregiver remained interested in participating, a time was scheduled for the caregiver's initial intake interview.

At the initial contact with the potential subject, the interviewer again described the study. Each potential participant was told that they were free to refuse to participate and may withdraw from the study at any time without penalty. The consent form was presented by the interviewer and included: an explanation of the research, the purpose of the study, the use of the results, and assurances of anonymity and confidentiality. Confidentiality and anonymity were assured through:

> 1) the use of caregiver identification numbers on all instruments
>
> 2) release of research data in aggregate form only
>
> 3) omission of agency names and/or identification in all presentations and reports
>
> 4) not providing confidential and interview data given by caregivers back to the agency
> (Given and Collins, 1986, p. 86).

After the consent form was signed, the caregivers became active participants in the study. The protocols of privacy, confidentiality, ethics of interviewing, and quality of nursing care, were followed by study personnel throughout all phases of the study.

Statistical Analysis of the Data

Data from the caregivers completing the initial intake interview (Phase I of the original study) were examined for this study. Univariate statistics were used to describe the self-care behaviors/practices of the sample, as well as the sociodemographic characteristics of the sample. Tables summarizing frequency distributions and percentages of subjects, by self-care practices and demographic variables are presented in Chapter V. Descriptive statistical analyses, allow for presentation of quantitative facts concerning the sample (Polit and Hungler, 1983).

Data from those caregivers completing the initial intake interview (Phase I of the original study) were also analyzed to examine the relationship between caregiver self-care behaviors/practices and the independent variables in the study (research question #2). A factor analysis was done using items one through twenty five from the self-care practices section of the Alzheimer's Family Care Study Questionnaire. The five self-care dimensions resulting from the factor analysis, are used to represent the dependent variable, caregiver self-care, in future data analysis procedures (Chapter V).

To answer research question #2, a hierarchical multiple regression analysis was utilized. The single dependent study variable (caregiver self-care) was "regressed" on the multiple independent study variables. Multiple regression analysis results in the R squared statistic, which is often referred to as the coefficient of determination (Polit and Hungler, 1983). R squared values, indicate the proportion of variance in Y (dependent variable/caregiver self-care) accounted for by the combined influence of the independent study variables. R values may vary from 0.0 to 1.0, (no negative R values) and represent the strength of the relationship (but not direction) between several independent and a single dependent variable (Polit and Hungler, 1983). Multiple regression analysis is clearly the statistical "test of choice" to answer research question #2.

In this study, significance of the relationship represented by R squared was determined by the F statistic. The F ratio provides the researcher with a way to determine if the calculated R is the result of chance fluctuations or statistically significant. that is, the researcher tests the null hypothesis that the population multiple correlation coefficient is equal to zero. F probabilities less than .05 were considered representative of a significant relationship between the dependent and independent variables. Beta values were observed to determine which independent variable contributed the most to changes in the dependent variable.

Summary

In this chapter, the research methodology was described and discussed. Specific topics addressed in each section included: the research question, study population and sample, operational definitions of all study variables, instrument development and scoring, data collection procedures, human subjects protection, and procedures for data analysis. An analysis of the data and findings relevant to the research questions are presented in Chapter V.

CHAPTER V

Data Presentation and Analysis

Overview

A description and analysis of the sample is discussed in this chapter. Data relevant to each of the research questions are presented to examine: the self-care practices of the caregiver participants and the relationship between the independent variables caregiver: age, sex, relation to Alzheimer's patient, marital status, employment, education, duration of caregiving, perceived health, caregiver's health problems, depression, social interaction, impact of caregiving on caregiver's schedule, amount of assistance from family/friends and the dependent variables representing caregiver self-care: physical-care, time-care, sleep-care, social-care, diet-care. Additional relevant findings from data analysis are also discussed.

Sample Characteristics

The sample for which data were available and analyzed for this study consisted of 120 persons designated as primary caregiver to an Alzheimer's Disease patient. Subjects in the study were primary caregivers: with an Alzheimer's patient residing in their home; related to the Alzheimer's patient; literate; ambulatory; and not blind. Caregivers reporting medical conditions of chronic psychoses or chronic obstructive pulmonary disease were excluded from study participation. In addition, caregiver participants reported no acute medical conditions such as cancer, uncontrolled cardiovascular disease or renal disease.

The 120 caregivers compose a convenience sample solicited for voluntary participation via: community agencies, home care agencies, day care centers, clinics, and Alzheimer's support groups throughout lower Michigan. Initial intake interviews completed on the 120 caregiver subjects in the sample compose the data utilized for analysis in this research study.

Sociodemographic Variables

The sociodemographic variables addressed in this study include caregiver: age, sex, marital status, employment, education, duration of caregiving and relation to Alzheimer's patient. Distributions concerning the sociodemographic variables in this study are outlined in Table 5.1. A brief synopsis of each sociodemographic variable distribution follows Table 5.1.

Table 5.1

Distribution of Subjects by Sociodemographic Variables.

Variable	Subjects	Percentages
Sex		
Male	32	27
Female	88	73
	n = 120	100%

Variable	Subjects	Percentages
Age		
25-35	2	2
36-45	9	7
46-55	19	16
56-65	45	38
66-75	40	33
76-85	5	4
	n = 120	100%
Employment		
Employed	39	32
Unemployed	81	68
	n = 120	100%
Marital Status		
Single/Never Married	4	3
Married	108	90
Widowed	5	4
Divorced	3	2
	n = 120	100%
Education		
Grade School or Less	9	7
Some High School	13	11
High School Graduate	30	25
Some College/Tech Training	46	38
College Graduate	13	11
Post Bachelors	9	7
	n = 120	100%
Duration of Caregiving		
1 year	22	18
2 years	17	14
3 years	27	22
4 years	16	14
5 years	10	9
6 years	9	8
7 years	5	4
8 years	3	2
9 years	3	2
10 years or Longer	8	7
	n = 120	100%

Variable	Subjects	Percentages
Familial Relationship to Alzheimer's Patient		
Spouse	85	71
Child	19	16
Daughter/Son In-law	14	12
Brother/Sister In-law	1	1
Other	1	1
	n = 120	100%

In sum, the typical caregiver in this study was: female, 62 years old, not employed, the spouse of the Alzheimer's patient, a high school graduate and had been in the caregiving role for approximately four years or less.

Non-Sociodemographic Variables

The non-sociodemographic variables in the study include: caregiver perceived health, caregiver health problems, caregiver depression, caregiver social interaction, impact of caregiving on the caregiver's schedule, and the amount of assistance provided by family and friends. The distributions of the aforementioned non-sociodemographic variables are presented in Table 5.2. A brief synopsis of the variable distributions will follow Table 5.2.

Table 5.2

Distribution of Subjects by Non-Sociodemographic Variables.

Variable	Subjects	Percentages
Caregiver Perceived Health		
Excellent	36	30
Good	62	52
Fair	20	17
Poor	2	1
	n = 120	100%
Number of Caregiver Health Problems		
(number of health problems reported out of 15 possible)		
Zero	43	36
1 - 5	61	50
6 - 10	11	10
11 - 15	5	4
	n = 120	100%
Caregiver Depression		
(scale of 1 - 4) 1 representing high level of depression and 4 representing a low level of depression		
1.0 - 1.7	70	58
1.8 - and above	50	42
	n = 120	100%
Caregiver Social Interaction		
How often is caregiver with friends/relatives?		
Everyday	1	1
Several Days Per/Week	22	18
Once A Week	30	25
2-3x Per Week	24	20
Once Per Month	11	9
5-10x Per Year	20	17
Less Than 5x Per Year	12	10
	n = 120	100%

Variable	Subjects	Percentages
How often are friends at caregiver's home?		
Everyday	1	1
Several Days Per/Week	8	7
Once A Week	15	13
2-3x Per Month	33	27
Once Per Month	31	26
Not At All In Past Month	32	27
	n = 120	100%
How often does caregiver visit at friend's home?		
Everyday	0	0
Several Days Per/Week	5	4
Once A Week	11	9
2-3x Per Month	33	27
Once Per Month	23	19
Not At All In Past Month	48	40
	n = 120	100%
How often does caregiver telephone family/friends?		
Everyday	30	25
Several Days Per/Week	59	49
Once A Week	13	11
2-3x Per Month	14	12
Once Per Month	1	1
Not At All In Past Month	3	2
	n = 120	100%
How often does caregiver write friend/relative?		
Everyday	0	0
Several Days Per/Week	10	10
Once A Week	17	14
2-3x Per Month	22	18
Once Per Month	25	21
Not At All In Past Month	46	38
	n = 120	100%
How often does caregiver attend religious services?		
Everyday	0	0
Several Days Per/Week	17	14
Once A Week	33	28
2-3x Per Month	5	4
Once Per Month	15	13
Not At All In Past Month	49	41
	n = 119	100%

Variable	Subjects	Percentages
Impact of Caregiving on Caregiver's Schedule		
(scale of 1 - 5) A value of 1 denotes a small impact of caregiving on the caregiver's schedule; a value of 5 denotes a large impact of caregiving on the caregiver's schedule.		
1.0 - 1.9	2	2
2.0 - 2.9	14	12
3.0 - 3.9	35	29
4.0 - 4.9	56	47
5.0	12	10
	n = 119	100%
Amount of Assistance From Family and Friends		
Scale values were computed by summing the number of times in the past three months caregivers were assisted with seven activities.		
0 - 50	63	53
51 - 100	27	23
101 - 150	18	15
151 - 200	5	4
201 - 250	4	3
251 - 368	3	0
	n = 120	98%

Discussion of Non-Sociodemographic Variables

Caregiver perceived health is used in this study as a subjective measure of the caregiver's health. In the sample 52% (n = 62) of subjects reported their own health status as 'good'. The next highest percentage of caregivers 30% (n = 36) reported their health status as excellent. The majority of caregivers in this sample perceive their health status to be 'good' to 'excellent'.

Caregiver health is used in this study as an objective measure of the caregiver's health. A measure of the caregiver's health problems was achieved by querying the caregiver's on 14 common health problems/illnesses. The largest percentage of caregivers reported 1-5 health problems (n=61, 50%). The next highest percentage of caregivers reported zero, or no health problems (n=43, 36%). The zero value was possible due to the response 'none' in the illness number category being equal to zero. Objectively, this sample of caregivers appears to be fairly healthy. What is unknown and warrants further investigation is how incapacitating the health problems reported are to the individual caregivers.

Caregiver depression was measured in this study using the CESD-20. The original CESD-20 scale ranges from values of 0 to 60 with 16 being the critical value representing the presence of depression. The original critical value of 16 corresponds to a value of 1.8 on the scale used in the current study. Among the sample of caregivers analyzed 58% (n=70) scored values of 1.8 or below. Therefore, over half of the caregivers sampled are depressed (using the CESD-20 criteria). Further discussion of the CESD-20 and the ability to capture characteristics of depression in this study sample is presented in Chapter VI.

Caregiver social interaction is a composite measure of six different aspects of social interaction. The distributions for each of the six social interaction items are reported in Table 5.2. In summary, the majority of caregivers in this sample sees family and/or friends several times a week. It is more likely that friends visit at the caregiver's home than vice versa. The caregivers in this sample are more likely to contact friends and family by phone than letter and the majority of attend religious services once a week or not at all. The response categories for caregiver social interaction do not reflect nuances such as, is it by choice that the caregiver does not attend religious services or visit at friends' homes, regardless of caregiving responsibilities.

Impact of caregiving on the caregiver's schedule was measured on a scale of 1 - 5. A value of 1 represented a minimal degree of impact (caregiving) on the caregiver's schedule and a value of 5 represented a great impact of caregiving on the caregiver's schedule. Over half of the sample (n=68, 57%) reported scores of 4 or greater. Caregiving does appear at this time to disrupt the schedules of this sample of caregivers to a great degree.

Amount of assistance from family and friends was calculated by multiplying (7 possible) activities of assistance by the number of times the caregiver was provided assistance in the past three months and summing the totals. The reported values for this sample ranged from 0 - 368. The values are low considering 7 activities of assistance were calculated over a 3 month period. Nevertheless, what is not clear in the values reported is how often specific activities of assistance were provided. That is, was one activity of assistance provided 20 times on one day in the past three months or was one activity of assistance provided one time per day for the last three months.

Unknown from this scale is whether the amount of assistance received is by caregiver choice (because it is not needed) or whether assistance is not available.

Dependent Variable

The single dependent variable in the study is a measure of caregiver self-care behaviors/practices. As discussed in Chapter Four, a factor analysis of the original twenty self-care questionnaire items resulted in five self-care variables representing the common characteristics or underlying dimensions of the original twenty-five self-care items. The five dependent variables were labeled: physical-care, time-care, sleep-care, social-care, and diet-care. The distributions and percentages for each of the five dependent variables is presented in Table 5.3. Following Table 5.3 is a brief narrative on the dependent variable distributions.

Table 5.3

Distributions of the Dependent Variables.

Variable	Subjects	Percentages
Physical-Care		
1.0 - 1.5 (never do this)	21	17
1.6 - 2.0	49	40
2.1 - 2.5	16	14
2.6 - 3.0 (do this regularly)	34	29
	n = 120	100%
Mean = 2.0		
Standard Deviation =.614		
Time-Care		
1.0 - 1.5 (never do this)	9	8
1.6 - 2.0	31	26
2.1 - 2.5	45	38
2.6 - 3.0 (do this regularly)	35	30
	n = 120	100%
Mean = 2.0		
Standard Deviation =.464		
Sleep-Care		
1.0 - 1.5 (never do this)	9	8
1.6 - 2.0	25	22
2.1 - 2.5	25	21
2.6 - 3.0 (do this regularly)	59	50
	n = 118	100%
Mean = 2.0		
Standard Deviation =.508		
Social-Care		
1.0 - 1.5 (never do this)	16	13
1.6 - 2.0	41	34
2.1 - 2.5	28	23
2.6 - 3.0 (do this regularly)	35	29
	n = 120	100%
Mean = 2.0		
Standard Deviation =.560		
Diet-Care		
1.0 - 1.5 (never do this)	5	4
1.6 - 2.0	18	15
2.1 - 2.5	20	17
2.6 - 3.0 (do this regularly)	77	64
	n = 120	100%
Mean = 3.0		
Standard Deviation = .488		

Discussion of Dependent Variables

As outlined in Chapter Four, the scoring for each of the self-care variables is the same. Response choices included: 1 = "never do this"; 2 = " do this occasionally"; 3 = "do this regularly". Therefore, low number scores indicate low participation in the self-care activity and high number scores indicate frequent participation.

Physical-care was distributed across responses with no obvious skewness. The items composing this variable were centered around exercise and body weight.

Time-care was also distributed across responses with adequate variation. The items composing the time-care variable had to do with the caregiver taking time for sleep, leisure, and social activities.

Sleep-care achieved adequate variation among the sample. The items composing sleep-care were specific to the caregiver's ease of achieving and maintaining 6 - 8 hours of sleep per night.

Social-care was well distributed across response values with no evidence of severe skewness. The items composing the social-care variable were centered around the caregiver's social "connectedness" and self "connectedness" (taking time for time by yourself).

Diet-care was the single dependent variable with extreme skewness. The reason for the skewness may have something to do with eliciting a socially desirable response or may reflect a sample of caregivers who are knowledgeable about diet recommendations and do in fact limit the amount of fat, cholesterol, refined sugar, and salt in their diets. Whatever the reason, this variable will be of limited use in further data analysis procedures due to a highly skewed distribution.

Research Questions

The research questions to be answered are:

Question 1. What are the reported self-care practices of a group of primary caregivers to Alzheimer's patients?

Question 2. What relationship do selected independent variables have with the dependent variable, caregiver performance of self-care behaviors?

Question 2a. Specifically, how are the following independent variables related to the Alzheimer's caregiver's self-care: physical-care, time-care, sleep-care, social-care and diet-care.

-caregiver age
-caregiver sex
-caregiver education
-caregiver employment
-caregiver marital status
-caregiver relationship to Alzheimer's patient
-duration of caregiving
-caregiver perceived health
-caregiver health
-caregiver depression
-caregiver social interaction
-impact of caregiving on caregiver's schedule
-amount of assistance from family and friends

Reliability of Instruments

Measures of reliability or internal consistency were conducted on the study instruments in a pilot study using a sample of 111 caregivers. The reliability coefficients (from the pilot study n= 111) for each of the study instruments were reported in Chapter Four, with a description of how each instrument was scored. Reliability coefficients for the five self-care variables were calculated using the study sample (n= 120) and were also reported in Chapter Four.

For reference, a "master" table is presented (Table 5.4). Table 5.4 shows each study scale or instrument, the number of caregivers it was tested on (n=111 or n=120) and the calculations of mean, standard deviation, and coefficient alpha when applicable for each scale or instrument.

Table 5.4

Mean, Standard Deviation, and Coefficient Alpha for all Study Scales.

Instrument/Scale	Subjects	Mean	S.D.	Alpha
Caregiver Perceived Health	n= 111	1.9	.75	NA
	n= 120	1.9	.73	NA
Caregiver Health	n= 111	4.0	3.3	NA
	n= 120	2.5	3.2	NA
Caregiver Depression	n= 111	1.8	.47	.87
	n= 120	1.8	.45	--
Impact of Caregiving on Caregiver's Schedule	n= 111	3.9	.81	.86
	n= 119	3.9	.79	--
Caregiver Social Interaction	n= 111	4.1	1.8	.86
	n= 120	4.1	1.6	--
Caregiver Assistance From Family and Friends	n= 111	2.7	1.7	NA
	n= 120	70.7	70.9	NA
Caregiver Self-care				
Physical-Care	n= 120	6.1	1.8	.51
Time-Care	n= 120	13.6	2.7	.74
Sleep-Care	n= 118	7.1	1.5	.64
Social-Care	n= 120	6.5	1.7	.64
Diet-Care	n= 120	7.7	1.5	.66

Note: S.D. = Standard Deviation

NA = Not Applicable

-- = Not Calculated

Data Presentation (1)

In this section a discussion of the data analysis used to address research Question 1 is presented.

Question 1. What are the reported self-care practices of a sample of primary caregivers to Alzheimer's patients?

The data analyzed to answer research Question 1 came from the caregivers' responses to the original 23 self-care questionnaire items. The respective distributions of each of the 23 questionnaire items are presented in Table 5.5. Reviewing the values in Table 5.5, it is obvious that some of the self-care items have highly skewed distributions. A majority of the skewed distributions occur with self-care items likely to elicit socially desirable answers (i.e. know what medications are for; follow medication label directions; use alcohol and drugs when stressed). Nevertheless, in general the sample of caregivers are favorably distributed on most of the self-care questionnaire items. Referring to the list of self-care items in Table 5.5, a brief discussion of the statistics for each self-care item is provided in the next section following Table 5.5.

Table 5.5

Distribution of Subjects by the Original 25 Self-Care Questionnaire Items.

Questionnaire Item	n / % Never Do This	n / % Do This Occasionally	n / % Regularly Do This	Mean	S.D.
1. Exercise 15-30 min. 3 times per week	45/38%	35/29%	40/33%	2.0	.84
2. Leisure activity for Fitness	23/19%	47/39%	50/42%	2.2	.75
3. Maintain Ideal Body Weight	39/33%	10/8%	69/58%	2.3	.93
4. Eat Variety of Foods	3/2%	13/11%	104/87%	2.8	.43
5. Limit fat & cholesterol	9/7%	23/19%	88/73%	2.7	.62
6. Limit Refined Sugar	11/9%	40/33%	69/57%	2.5	.66
7. Limit Amount of Salt	9/8%	30/25%	80/67%	2.6	.63
8. Eat Breakfast Daily	16/13%	20/17%	84/70%	2.6	.72
9. More than 3 Cups of Caffeinated Beverages Per Day	53/45%	23/19%	43/36%	1.9	.89
10. Follow Medication Label Directions	------	7/6%	113/94%	2.9	.24
11. Know What Medications Are For	3/3%	6/5%	109/92%	2.9	.38
12. Take Drugs Without Dr.'s Prescription	66/57%	31/27%	19/16%	1.6	.76
13. Sleep 6-8 Hrs/Night	11/9%	27/23%	79/68%	2.6	.66
14. Have Uninterrupted Sleep	37/32%	53/45%	27/23%	1.9	.74
15. Sleep Easily Without Medications	7/6%	24/20%	88/74%	2.7	.58

Table 5.5 --Continued--

Questionnaire Item	n / % Never Do This	n / % Do This Occasionally	n / % Regularly Do This	Mean	S.D.
16. Drink 6-8 Cups of Water Per Day	31/26%	42/35%	47/39%	2.1	.80
17. Take Laxatives	86/73%	27/23%	5/4%	1.3	.55
18. Observe Body for Cancer Signs	35/30%	50/42%	33/28%	2.0	.77
19. Take Time for Myself Daily	19/16%	50/42%	50/42%	2.3	.72
20. Report Unusual Signs/Symptoms Promptly	13/11%	35/29%	71/60%	2.5	.69
21. In Normal Day Walk One Mile	40/33%	42/35%	38/32%	2.0	.81
22. Use Alcohol and/or Drugs When Stressed	97/82%	18/15%	4/3%	1.2	.49
23. Go Out With Friends Daily	32/27%	57/47%	31/26%	2.0	.73

Discussion of Data Relevant to Research Question 1

Exercise and Fitness

In the exercise and fitness arena caregivers score low participation with 38% (n=45) reporting they never exercise 15-30 min., 3 times per/week, and 33% (n=40) never walk one mile in a normal day. Nevertheless, 42% (n=50) of caregivers report regular participation in a leisure activity for fitness.

Diet and Body Weight

In regard to diet and body weight, a majority of caregivers report regularly limiting: sugar (57%, n=69) fat and cholesterol (73%, n=88) and salt (67%, n=80) in their diets'. Furthermore, 45% (n=53) of caregivers report never drinking more than three cups of caffienated beverages per day. The caregivers' intake of water was fairly equally distributed with 39% (n=47) of the sample claiming to drink 6-8 cups of water per day on a regular basis. Eating breakfast daily was practiced by this sample of caregivers, with 70% (n=84) reporting breakfast as a regular activity. Maintaining ideal body weight does not appear to be a problem for over half of the caregivers, as 58% (n=69) report doing this regularly.

It appears paradoxical that over half of the caregivers regularly maintain ideal body weight yet exercise is a regular practice of under half the study sample. It is important to note that the caregiver's ideal body weight was left to the caregiver's subjective assessment of their "ideal" weight rather than a calculated ideal body weight.

Medication and Alcohol

As mentioned earlier, when questioned about medication, drug and/or alcohol use an overwhelming majority of caregivers indicate the socially desirable response. For example, 82% (n=97) of caregivers claimed never to use alcohol or drugs when stressed. Similarly, within the sample of caregivers 94% (n=113) report following medication label directions and 92% n=109) report knowing what the medications they take are for.

Approximately half of the sample 57% (n=66) report never taking drugs without a Doctor's prescription.

Sleep

A majority of the sample reported: sleeping 6-8 hours per/night (68%, n=79) and sleeping easily without medication (74%, n=88). However, for unknown reasons, the caregivers' sleep is interrupted frequently as only 23% (n=27) of caregivers report uninterrupted sleep as a regular occurrence. Further investigation is necessary to determine if sleep disturbances are due to caregiving responsibilities or other factors such as caregiver age.

Caregiver Care of Self

In regard to general care of themselves, caregivers vary according to the specific behavior. Queried on taking time for themselves each day, 42% (n=50) if caregivers in the sample report doing this occasionally and 42% (n=50) report doing this regularly. A majority of caregivers (60%, n=71) indicate they regularly and promptly report any unusual signs or symptoms. Going out with friends daily is an occasional occurrence for nearly half of the sample (47%, n=57). Another occasional activity for approximately half the sample (42%, n=50) involves observing their body for signs of cancer. It is interesting to note that a majority of caregivers indicate they report unusual signs or symptoms regularly, yet observing for signs or cancer (often not accompanied by symptoms) is done only occasionally by under half of the total sample.

In summary, the caregivers in the sample analyzed report the desired pattern of responses and appear to have some knowledge or understanding of positive self-care practices. A limitation of these self-care questionnaire items is the lack of discrimination in the response categories. Providing only three response choices limits variation and may encourage the socially desirable response, as few people like to admit "never" participating in a recommended self-care activity. The 23 self-care items composing the self-care scale or instrument used in this study have not been tested previously. Therefore, interpreting obtained values as true measures of the self-care practices/behaviors of this sample of caregivers is tenuous.

Data Presentation (2)

In this section a discussion of the data analysis used to answer research Questions 2 and 2a is presented.

Question 2. What relationship do selected variables have with the Alzheimer's caregivers' performance of self-care?

Specifically:

Question 2a. How are the following independent variables related to Alzheimer's caregivers' self-care?

- caregiver age
- caregiver sex
- caregiver education
- caregiver employment
- caregiver marital status
- caregiver relation to Alzheimer's patient
- duration of caregiving
- caregiver perceived health
- caregiver health
- caregiver depression
- caregiver social interaction

- impact of caregiving on caregiver's schedule
- amount of assistance from family and friends

To answer Questions 2 and 2a, a hierarchical multiple regression procedure was used to analyze the data. Regression analysis can be used to observe the effect of changes in the independent variables on the dependent variables (O'Muircheartaigh and Francis, 1981). When seeking to analyze the relationship between several independent variables and a single dependent variable, multiple regression analysis is the statistical "test of choice".

Preliminary work was necessary to prepare the study data for regression analysis. As discussed previously the original 23 self-care questionnaire items (representing the dependent variable caregiver self-care) were entered into a factor analysis to produce a smaller set of variables with common characteristics or underlying dimensions. The resulting five self-care dependent variables were labeled according to the common characteristics or dimensions represented.

Physical-Care: (self-care items 1, 3, 21)
Items included centered around physical exercise and maintaining ideal body weight.

Time-Care: (self-care items 2, 13, 15, 19, 23)
Items included focused on caregiver taking time for themselves in leisure, sleep, and social contact.

Sleep-Care: (self-care items 13, 14, 15)
Items specific to caregiver's ease achieving sleep, length of sleep, and quality of sleep.

Social-Care: (self-care items 2, 19, 23)
Items pivot on caregiver involvement in social or leisure activities.

Diet-Care: (self-care items 5, 6, 7)
Items converge on caregiver's effort to limit cholesterol, fat, sugar and salt in his or her diet.

In a correlation matrix involving all variables used in this study, multicollinearity among the independent variables was not observed to be a problem. The frequency distributions of the five dependent variables were presented earlier in this chapter. Before proceeding with a discussion of the multiple regression analysis, a brief review of the independent variables is presented.

The original list of independent study variables included seven sociodemographic variables and six non-sociodemographic variables:

Sociodemographic Variables

1. caregiver age
2. caregiver sex
3. caregiver education
4. caregiver marital status
5. caregiver employment
6. duration of caregiving
7. relation of caregiver to Alzheimer's patient

Non-Sociodemographic Variables

1. caregiver perceived health
2. caregiver health
3. caregiver depression
4. impact of caregiving on caregiver's schedule
5. social interaction of caregiver
6. assistance from family and friends

Among the sociodemographic variables 'marital status' and 'relation of caregiver to Alzheimer's patient' were collapsed into a new single variable titled 'spouse/non-spouse'. The variables were combined for further analysis due to the high proportion of caregivers married to the Alzheimer's patient in their charge. The 'spouse/non-spouse' variable indirectly gives the caregiver's marital status and combines all other types of relations into the non-spouse category. Therefore six sociodemographic variables are now available for the multiple regression analysis.

Among the non-sociodemographic variables six variables were originally proposed as listed above. These six variables will be used for the multiple regression analysis. A total of twelve independent variables (sociodemographic + non-sociodemographic) are now available for the regression analysis.

Twelve independent variables is a large number of variables to include in a regression analysis equation. The problem of adding many independent variables to a regression equation is based on the fact that, "it is rare to find many predictor variables that correlate well with a criterion measure while correlating only slightly with one another" (Polit and Hungler, 1983, p. 539). Redundancy is difficult to avoid as more variables are added to the prediction equation. "Typically, inclusion of independent variables beyond four or five does little to improve the accuracy of prediction" (Polit and Hungler, 1983, p. 540).

In an effort to reduce the number of independent variables (twelve) entered into the regression analysis, variables with common underlying dimensions were combined in groups. The process of "grouping" the twelve independent variables was done intuitively and resulted in the following four groups:

Group 1 <u>Demographics</u>	- caregiver age - caregiver sex - caregiver education - caregiver employment - caregiver spouse/non-spouse - duration of caregiving
Group 2 <u>Health Status</u>	- caregiver perceived health - caregiver health

Group 3 Psychological Status	- caregiver depression - impact of caregiving on the caregiver's schedule
Group 4 Social Activity	- social interaction of caregiver - amount of assistance from family and friends

As outlined above, the four new independent variable groups are self-explanatory. 'Demographics' includes all the original independent demographic variables. 'Health Status' includes the two original independent variables concerning caregiver health. 'Psychological Status' was created by combining the independent variables with a perceptual dimension (i.e. caregiver depression and the impact of caregiving on the caregivers schedule). 'Social Activity' was formed by combining the independent variables with a behavioral dimension (i.e. social interaction of the caregiver and assistance from family and friends).

Therefore, after various steps in data preparation there are now four groups of independent variables (demographics, health status, psychological status, social activity) and five dependent variables (physical-care, time-care, sleep-care, social-care, diet-care) which will be utilized in the regression analysis. The following section is a discussion of how the hierarchical regression analysis was performed and results used to answer research questions 2 and 2a.

Regression Analysis

In a hierarchical regression analysis 'hierarchical' denotes the researcher has control over how (in what sequence) the independent variables are entered into the regression equation.

To appreciate fully the importance of variable sequence or order in multiple regression, one must grasp the concept that as each independent variable is entered into the regression analysis the variable entered accounts for the most variability in Y (dependent variable) after any or all previous independent variables are accounted for or controlled. Therefore, changing the sequence or order of the independent variables entered in the regression will result in different R squared change values.

The sequences of independent variables utilized in the regression analyses for this study were formulated after reviewing the data with a statistical consultant. A decision was made to alter the order of the independent variables three ways in three separate regression equations. The three independent variable sequences correspond to independent variable groups: Group 2 (health status) Group 3 (psychological status) and Group 4 (social activity). Each of the three aforementioned variable groups were rotated into the last variable position entered in the three regression equations. Group 1 (demographics) was held constant as the first group of independent variables entered in each regression analysis because the Group 1 variables contributed the least to a change in R squared. Table 5.6 outlines the three regression analysis procedures and the results obtained. Following Table 5.6, the correlation values and beta values for all independent and dependent variables are presented in a separate table (Table 5.7).

Table 5.6

Results of Hierarchical Regression Analyses 1, 2, and 3.

	Regression Analysis #1	Regression Analysis #2	Regression Analysis #3
	Demographics Social Activity Health Psychological	Demographics Health Psychological Social Activity	Demographics Social Activity Psychological Health
Physical-Care	$R^2 = .25$ $R^2\Delta = .019$ $F = .266$	$R^2 = .25$ $R^2\Delta = .022$ $F = .212$	$R^2 = .25$ $R^2\Delta = .102$ $F = .001$
Time-Care	$R^2 = .50$ $R^2\Delta = .251$ $F = .000$	$R^2 = .50$ $R^2\Delta = .019$ $F = .138$	$R^2 = .50$ $R^2\Delta = .014$ $F = .243$
Sleep-Care	$R^2 = .45$ $R^2\Delta = .228$ $F = .000$	$R^2 = .45$ $R^2\Delta = .005$ $F = .606$	$R^2 = .45$ $R^2\Delta = .057$ $F = .005$
Social-Care	$R^2 = .39$ $R^2\Delta = .156$ $F = .000$	$R^2 = .39$ $R^2\Delta = .027$ $F = .102$	$R^2 = .39$ $R^2\Delta = .013$ $F = .327$
Diet-Care	$R^2 = .08$ $R^2\Delta = .003$ $F = .823$	$R^2 = .08$ $R^2\Delta = .013$ $F = .471$	$R^2 = .08$ $R^2\Delta = .027$ $F = .291$

Note: R^2 = R squared
$R^2\Delta$ = R squared change
F = Significance of F change

Table 5.7

Correlation/Beta Values for all Independent/Dependent Variables.

Dependent Variable: Physical-Care

Independent Variables:	r	beta
Family Relation	-.018	-.031
Duration	-.142	-.139
Employment	.131	.086
Sex	.035	.116
Education	-.018	-.220
Age	-.008	-.028
Assistance Family/Friend	.014	-.059
Social Interaction	.122	.168
Perceived Health	.341	.174
Caregiver Health Problems	-.328	-.264
Impact on Schedule	-.132	.027
Depression	-.304	-.170

Dependent Variable: Time-Care

Independent Variables:	r	beta
Spouse/Nonspouse	-.199	-.103
Duration	.079	.114
Employment	.084	-.026
Sex	-.034	.041
Education	.207	.031
Age	-.082	-.110
Assistance Family/Friends	.112	.030
Social Interaction	.261	.146
Perceived Health	.321	.010
Caregiver Health Problems	-.298	-.130
Impact on Schedule	-.330	-.076
Depression	-.644	-.551

Table 5.7 -Continued-

Dependent Variable: Sleep-Care

Independent Variables:	r	beta
Spouse/Nonspouse	-.161	-.040
Duration	.106	.157
Employment	.121	.025
Sex	.084	.117
Education	.208	-.020
Age	-.081	-.133
Assistance Family/Friends	.109	.040
Social Interaction	.155	.061
Perceived Health	.230	-.136
Caregiver Health Problems	-.380	-.298
Impact on Schedule	-.266	-.076
Depression	-.565	-.523

Dependent Variable: Social-Care

Independent Variables:	r	beta
Spouse/Nonspouse	-.181	-.133
Duration	.037	.049
Employment	.030	-.062
Sex	-.132	-.040
Education	.157	.071
Age	-.058	-.056
Assistance Family/Friends	.086	.014
Social Interaction	.289	.182
Perceived Health	.309	.140
Caregiver Health Problems	-.152	.052
Impact on Schedule	-.301	-.054
Depression	-.551	-.437

Dependent Variable: Diet-Care

Independent Variables:	r	beta
Spouse/Nonspouse	-.021	-.069
Duration	-.003	-.005
Employment	-.038	-.005
Sex	-.133	-.148
Education	-.024	.069
Age	.061	.118
Assistance Family/Friends	.109	.117
Social Interaction	.090	.003
Perceived Health	-.030	.020
Caregiver Health Problems	.157	.198
Impact on Schedule	-.048	-.008
Depression	-.071	-.065

Discussion of Results of Regression Analyses

Referring to Tables 5.6 and 5.7, each of the dependent variables is reviewed separately and values obtained in regression analysis #1, #2, and #3, discussed.

Physical-Care

Looking across Table 5.6 at dependent variable 'physical-care', the R squared values obtained in regression analyses #1, #2, and #3 (R squared = .25) indicate that 25% of the variance in the dependent variable 'physical-care' is accounted for by all the independent variables together. The independent variable group contributing most to the change in R squared is found in regression analysis #3 where 'health status' is the last independent variable group entered. 'Health status' is composed of the independent variables 'caregiver perceived health' and 'caregiver health'. Reviewing the beta values (Table 5.7) pertinent to regression analysis #3, 'caregiver health problems' (number of caregiver health problems reported out of 15 possible) contributes most to the change in R squared (beta = -.264). 'Caregiver health problems' is inversely related to the dependent variable 'physical care' (r = -.328). The inverse relationship of 'caregiver health problems' and 'physical care' seems logical in that as caregiver health problems increase and/or decrease the caregiver's ability to participate in physical care activities will decrease and/or increase.

Time-Care

Reviewing regression analysis #1, #2, and #3 regarding dependent variable 'time-care', the highest R squared values in

Table 5.6 are observed (R squared = .50). The R squared value of .50 indicates the independent variables together account for 50% of the variance in the dependent variable 'time-care'. In relation to dependent variable 'time-care' regression #1 resulted in a significant value (F = .000) for the change in R squared. The final independent variable group entered in regression #1 is 'psychological status' which is composed of independent variables 'caregiver depression' and 'the impact of caregiving on the caregiver's schedule. Reviewing the beta values in Table 5.7 pertinent to dependent variable 'time-care' the independent variable 'caregiver depression' is observed to contribute the most to the change in R squared (beta = -.551). 'Caregiver depression' is also the independent variable most strongly related (inversely) to 'time-care'.

The dependent variable 'time-care' focuses on the caregiver taking time for themselves in leisure, sleep and social activities. The statistical values reported in regression #1 in relation to the dependent variable 'time-care' appear to make sense. It is sensible that caregiver depression could have an inverse relationship with the caregiver's leisure, sleep and social activities.

<u>Sleep-Care</u>

As seen in Table 5.6 the dependent variable 'sleep-care' achieved significant R square changes in both regression analysis #1 and #3 (F = .000 and F = .005). The variance accounted for in the dependent variable 'sleep-care' by all the independent variables was 45% (R squared = .45). Regression analysis #1 produced the greatest change in R squared (.228) and this change was significant (F = .000). The sequence of independent variables entered in regression #1 ended with the variable group 'psychological status'. Variable group 'psychological status' is composed of independent variables 'caregiver depression' and 'impact of caregiving on the caregiver's schedule. Reported beta values for regression #1 (see Table 5.7) show 'caregiver depression' as the independent variable contributing most to the change in R squared (beta = -.523). 'Caregiver depression' is also the independent variable with the strongest correlation value to 'sleep-care' (r = -.565). The inverse relationship of 'caregiver depression' and 'sleep-care' seems logical as persons experiencing depression often report sleep problems and/or disturbances.

The second significant R squared change observed with dependent variable 'sleep-care', occurred in regression analysis #3. The sequence of independent variables in regression analysis #3 was such that the 'health status' variable group (composed of independent variables: 'caregiver perceived health' and 'caregiver health') was entered last. 'Caregiver health' (measured by the number of health problems the caregiver reports out of 15 possible) was the independent variable with the second highest beta value in the regression analysis (beta = -.298). The relationship of 'caregiver health' and 'sleep-care' is significant (F = .005) but less significant than the relationship between 'caregiver depression' and 'sleep-care' (F= .000). In regard to correlation values, independent variable 'caregiver depression' (r = -.565) is more strongly, and inversely related to dependent variable 'sleep-care' than the independent variable 'caregiver health' (r = -.380).

Social-Care

Referring to Table 5.6, the independent variables in total account for 39% (R squared = .39) of the variance in the dependent variable 'social-care'. Regression analysis #1 resulted in a significant value for the change in R squared (F = .000). The final variable group in the sequence of independent variables entered in regression #1 was 'psychological status'. The variable group 'psychological status' is composed of independent variables, 'caregiver depression' and 'impact of caregiving on the caregiver's schedule'. According to the beta values in Table 5.7, 'caregiver depression' is the independent variable contributing the most to the change in R squared (beta = -.437). The dependent variable 'social-care' focuses on the caregiver's social and/or leisure contacts. The inverse statistical relationship (r = -.551) of 'caregiver depression' and 'social-care' appears logical, as levels of depression may affect the caregiver's desire for, or success in, social contact.

Diet-Care

The dependent variable 'diet-care' was essentially a "lost" variable with only 8% (R squared = .08) of variance explained by all the independent variables together. As mentioned earlier, the low R squared values are not a surprise due to the poor distribution (highly skewed) of the diet-care questionnaire item responses. The explained variance in relation to 'diet-care' is low because there was highly skewed variation in the questionnaire item responses to begin with. No relationship was observed between the independent variables and the dependent variable 'diet-care' in regression #1, #2 or #3.

Summary

In sum, there is evidence from the data that this sample of caregivers is knowledgeable about positive self-care practices. Knowledge and practice are not always related however, and in some areas the caregivers show need for improvement (exercise, fitness, observing body for signs of cancer). To investigate the relationship of the dependent variable, caregiver self-care and the various independent variables, several steps in data preparation were necessary. The results of the final multiple regression analyses provide evidence of a relationship between the following dependent and independent variables:

Dependent Variable	Independent Variable
Physical-Care	Caregiver Health
Time-Care	Caregiver Depression
Sleep-Care	Caregiver Depression and Caregiver Health
Social-Care	Caregiver Depression
Diet-Care	None

Further discussion of the findings are presented in Chapter VI. Also in Chapter VI are recommendations for nursing practice and future research based on the results of this study.

CHAPTER VI

Summary and Conclusions

Overview

A summary and interpretation of the research findings are presented in this chapter. The sociodemographic and non-sociodemographic characteristics of the study sample are discussed and compared to sample characteristics of other research. The findings related to the research questions are presented and compared to findings from other studies. Lastly, the implications of the findings for nursing practice, education and future research are addressed.

A brief review of the chapter sequence to this point is presented before proceeding with Chapter VI. Chapter I included an introduction and background of the study problem. Study variables were defined as were study assumptions and limitations. Chapter II covered the development of the conceptual framework used in the study and conceptual definitions of the study concepts. In Chapter III, a literature review was presented to link the concepts and variables of this study to past research. Chapter IV included a detailed description of the methodology and procedures used to conduct this study. The analysis of all data and data presentation composed Chapter V. As mentioned above, Chapter VI (as the final study chapter) is devoted to: summary and conclusions; implications for nursing practice and future research in the study area.

Sociodemographic Characteristics of the Sample

The sociodemographic characteristics examined in this study include caregiver: age, sex, marital status, relation to Alzheimer's patient, employment, education and duration of caregiving.

Age. Among the sample in this study, well over half (n= 85, 71%) of the 120 caregivers were in the 56-75 age range. The finding is supported by two facts from the Alzheimer's caregiver literature: 1) the majority of Alzheimer's caregivers are spouses of the Alzheimer's patients and 2) most Alzheimer's patients are 65 years or older (ADRDA, 1987). A discussion of the different stressors befalling younger -vs- older caregivers was provided in Chapter III. The comments here pertain to the variable 'age' and its relation to study participants self-care.

Among the sample, knowledge of and participation in self-care activities was recorded as favorable. That is, the caregivers in general received high scores on their knowledge of "prescribed" self-care behaviors and their participation in them. Therefore it cannot be said that self-care and/or health promotion is relegated to the younger generation. No prior studies were found in which Alzheimer's caregivers' self-care practices were investigated in relation to the caregiver's age. The study data offers one sample group to which future research groups may be compared.

Sex. Among the sample in this study were 32 male caregivers (27%) and 88 female caregivers (73%). Although Alzheimer's Disease does not exhibit a gender preference, the act of caregiving does. Because of persistent sex-role differences, and greater female life expectancy, women are much more likely than men to assume responsibility for providing direct care (Brody, 1981; Shanas, 1979; Troll, 1971). Because this sample is 73% female the self-care data also reflects a greater female input. At this time, any effort designed to monitor or activate caregiver self-care would be utilized on a greater proportion of females than males due to the greater percentage of female caregivers. The self-care needs of older women have been documented (McElmurry and LiBrizzi, 1986) and the experience of older women in caregiving roles has been investigated (Robinson, 1986). What remains to be researched is what the self-care needs of the female Alzheimer's caregiver are and how these self-care needs may best be met and monitored in the primary health care system.

<u>Marital Status</u>. Among the sample in this study, 108 (90%) of the 120 caregivers were married. Finding the majority of this sample married was not surprising in light of the research supporting the observation that most caregivers are the spouses of the Alzheimer's patients (ADRDA, 1987; Johnson, 1983; Johnson and Catalano, 1983). In the caregiver literature spousal caregivers are portrayed at high risk for: strain; (Cantor, 1983) poor mental health; (Gilhooly, 1984) low levels of well-being and poor self-rated health (George and Gwyther, 1986). The consensus in the literature is that the closer the caregiver/patient bond the greater the caregiver's 'burden'.

In this study, the fact that most caregivers are spousal caregivers did not appear to impinge on the caregivers' self-care practices. It may be that this sample of caregivers are not encumbered by their caregiving duties at this point in time and there is ample opportunity for the caregivers' self-care activities. Should these spousal caregivers become more entrenched in their caregiving duties, it is predicted in the literature that the spouse caregiver will neglect his or her own self-care needs to meet the caregiving demand (Pratt et al. 1987). Conversely, a non-spouse caregiver is less likely to jeopardize their own health to accommodate the patient (Caserta et al. 1987).

Relation to the Alzheimer's Patient. Among the sample in this study, 85 caregivers (71%) were spouses of the Alzheimer's patient. As discussed above, spousal caregivers are at risk for and appear to endure more negative aspects of caregiving than non-spouse caregivers. The demographic distribution in this study supports the observation that spousal caregivers compose the major caregiving group for Alzheimer's patients in the home. The greater challenge and question is how best to motivate and facilitate the spousal caregiver's self-care ability to maintain the viability of the spouse caregiver as caregiving requirements become more demanding.

Education. Among the sample of caregivers in this study, 30 (25%) were high school graduates and 46 (38%) had some college or technical training. Compared to other samples in the literature the participants in this study were well educated.

In general the study sample appeared knowledgeable in self-care issues, however, knowledge does not guarantee practice. Again, the greater challenge is to ensure that self-care knowledge becomes self-care practice among the caregiving population. This study is a small step toward that end.

Duration of Caregiving. Among the sample of caregivers 66 (54%) had been in the caregiving role three years or less and 92 (77%) had been in the caregiving role for five years or less. As discussed in Chapter III, the literature includes research linking 'duration of caregiving' to both positive and negative caregiver outcomes. In this study the duration of caregiving had been five years or less for the majority of the sample and most caregivers do not report caregiving as a major obstacle in their lifestyles'. The relatively short duration of caregiving observed in this study sample may well be a factor in the positive responses offered by the participants in regard to satisfaction in their caregiving role.

Employment. Among the sample in this study, 39 (32%) caregivers were employed and 81 (68%) unemployed. Employment is most often a function of caregiver age, with younger caregivers (below 65 years) more likely to be employed (Colerick and George, 1986). The literature is inconsistent with evidence that caregiver employment is in one case an added burden and in another case a productive outlet for the caregiver. The majority of caregivers in this sample are unemployed and report moderate to high levels of morale and mental health at this time. Lack of employment does not appear to be a negative influence on the caregiving sample at this time.

In sum, the sample in this study consisted of generally older, unemployed, female, spouse caregivers. This distribution of age, employment, sex and relation to Alzheimer's patient, is consistent with other study samples in the Alzheimer's caregiver literature. Caregiver education level was generally higher than in most studies reviewed. Realizing that the education level reported pertains most often to the female spouse. Duration of caregiving was relatively short for most study participants and recognizing the stages of Alzheimer's Disease, most of the sample are most likely dealing with a patient in the early stages of the Disease. As discussed later in this Chapter, the sociodemographic variables produced the smallest R square change when entered in the multiple regression analysis. In other words, caregiver demographics were the independent variables found to be most weakly related to the dependent self-care variables.

Non-Sociodemographic Characteristics of the Sample

The non-sociodemographic variables addressed in this study were caregiver: health, perceived health, depression, social interaction, amount of assistance from family and friends, and the impact of caregiving on the caregiver's schedule.

Caregiver Health. The sample analyzed in this study appeared to be in good health. Of the 120 caregivers, 43 (36%) reported zero health problems and 61 (50%) reported one to five health problems. These two groups account for 104 (86%) of the entire sample. As mentioned in Chapter III most prior research has been investigations of caregiver health as a product or consequence of caregiving. The approach in this study is slightly different -- investigating what relationship caregiver health has with caregiver self-care.

Reviewing the results of this study, it is difficult to say what occurred first: the caregiver's good health or the caregiver's good self-care practices. Nevertheless, caregiver health as an independent variable produced the greatest change in R squared in the regression analysis with dependent variables: physical-care and sleep-care. These relationships will be discussed in depth later in this Chapter.

Caregiver Perceived Health. The majority of the sample analyzed in this study perceived their own health as good to excellent. Of the 120 participants, 62 (52%) reported a perceived health status of 'good' and 36 (30%) a perceived health status of excellent. As mentioned in Chapter III, no previous studies were found in which caregiver perceived health was investigated in relation to self-care. In the regression analyses presented later in this Chapter, the variable 'caregiver perceived health' was found to contribute less to the change in R squared than the other health variable 'caregiver health'. Nevertheless, the high scores recorded in regard to this sample's perceived health are evidence that this group of caregivers perceive their own health as good at this point in time.

Caregiver Depression. The numerical scale used in this study to gauge the level of caregiver depression ranged from a low of 4 to a high of 1. Among the sample analyzed 43 (35%) caregivers registered depression values of 1.0 - 1.5 and 48 (39%) of caregivers registered depression values of 1.6 - 2.0. These two groups together account for 74% (n= 88) of all caregivers in the sample. Clearly the majority of the sample reported a relatively high level of depression (on the CESD-20) at this point in time.

In light of the often atypical presentation of depression in the elderly (those over 65) and the old old (those over 75), it is important to digress and mention the limitations of using a depression scale such as the CESD-20 on this sample of caregivers. The existing literature indicates that depression may be quantitatively different among the elderly and old old populations (Weiss, Nagel, Aronson, 1986). "Specific symptoms of depression reported most commonly in the elderly include: loss of self-esteem, feelings of helplessness, and complaints of cognitive deficit" (Weiss, Nagel, Aronson, 1986, p.215). Based on this information Weiss, Nagel and Aronson (1986) compared the contents of six currently used depression rating scales and found that for the most part the scales do not address the symptoms reported to be more common among depressed elderly. Furthermore, none of the scales have been validated on the old old population.

In the Weiss, Nagel, Aronson (1986) study the six scales compared included the: Hamilton Depression scale (HAM-D), Inventory of Psychic and Somatic Complaints of the Elderly (IPSCE), Zung Self-Rating Depression Scale (ZUNG), Beck Depression Inventory (BECK), Center for Epidemiologic Studies Depression Scale (CESD), Geriatric Depression Scale (GDS). All of the aforementioned scales capture the DSM-III criteria for depression. However, when comparing the scales using thirteen characteristics of depression in the elderly the scales differ significantly.

Of all six scales compared, the CESD included the fewest (2) of the thirteen characteristics of depression in the elderly. The GDS contained the highest number (6) of the thirteen characteristics of depression in the elderly (Weiss, Nagel, Aronson, 1986). Thus, it would appear that attempts to assess the prevalence of depression in the geriatric population, particularly the old old may be limited by the lack of a suitable instrument. The potential benefits of such an instrument may be a decrease in the morbidity and mortality associated with depression as a disorder highly amenable to therapeutic interventions.

In regard to this study, it may be necessary to not only consider caregiver age in relation to depression, but to factor in caregiving as an additional criteria when assessing depression among elderly caregivers. The validity of the study results in regard to depression may have been improved by utilizing a depression scale such as the GDS which includes the greatest number of criteria relevant to depression in the elderly.

As discussed later in this Chapter, the independent variable 'caregiver depression' produced the largest R square change in regression analyses with the dependent variables: time-care, sleep-care and social-care. On the basis of the regression analyses in this study 'caregiver depression' more than any other independent variable in the study merits further investigation. As mentioned in Chapter III, caregiver depression has been researched as a consequence of caregiving but not as a variable affecting caregiver self-care. The relationship of caregiver depression and the dependent variables: time-care, sleep-care and social-care is discussed later in this Chapter.

Caregiver Social Interaction. As noted in Chapter III, caregiver social interaction has previously been linked to several aspects of caregiving. However, the relationship of caregiver social interaction and caregiver self-care is one aspect that has not previously been investigated or reported on. Among the sample analyzed in this study, social interaction is not a problem for 50 - 75% of the caregivers responding to each of the six social interaction dimensions. Unfortunately, due to the nature of the questionnaire items used, it is impossible to determine if the caregiver's social interaction is dictated by caregiving responsibilities or caregiver choice. Results of the multiple regression analyses show no relationship between the independent variable social activity and the dependent self-care variables. Additional research is required to determine if caregiver social activity is truly unrelated to the caregiver's self-care practices and behaviors.

Caregiver Amount of Assistance From Family and Friends. Caregivers composing the sample analyzed in this study are currently observed to receive little assistance from family or friends in executing the duties of caregiver. Unfortunately, the data does not indicate whether caregivers chose not to receive assistance or whether assistance was not available to the caregiver. In any case, the independent variable 'amount of assistance from family and friends' contributed little in the multiple regression analyses. The 'amount of assistance' variable was found to have no relationship with the dependent self-care variables. Like the variable 'caregiver social interaction' additional research is necessary to determine if the amount of assistance the caregiver receives truly has no relationship with the caregivers self-care activities or behaviors.

Impact of Caregiving on the Caregiver Schedule. A scale of 1 (low) to 5 (high) was used to gauge the impact of caregiving on the caregiver's schedule. Of the 119 subjects responding, 47% (n= 56) scored values of 4.0 - 4.9 and 10% (n= 12) scored a value of 5.0. Therefore, slightly over half of the sample 57% (n= 68) report caregiving has a moderate to large impact on their schedule. As addressed in Chapter III, no previous studies were found linking self-care to the impact of caregiving on the caregiver's schedule.

In sum, the sample of caregivers in this study are portrayed via the non-sociodemographic variables as generally: in good health, perceiving themselves to be in good health, socially active and receiving minimal assistance from family and friends. Another aspect of the caregiving sample is revealed in relation to the non-sociodemographic variables 'caregiver depression' and 'impact on schedule'. The Depression level as measured by the CESD is moderate to high for the majority of the sample. In addition, the activities of caregiving impact this sample group's schedule a moderate to large degree. Of the six non-sociodemographic variables entered in the multiple regression analysis, only two produced changes in R squared at a level of significance (F < .05) -- 'caregiver health' and 'caregiver depression'. The two aforementioned variables will be discussed further in the Chapter when findings related to the research questions are presented.

Before continuing with Chapter VI, it is important to comment on some concepts from Pender's (1987) Health Promotion Model that were not included in the conceptual framework for this study. Referring back to Chapter II, Figure 2, it is clear that the Cognitive-Perceptual factors of the original Health Promotion Model were not incorporated when constructing the model for this study (except for 'perceived health status'). The absence of these Cognitive-Perceptual factors has potentially weakened the strength of the present study and inclusion of these Cognitive-Perceptual factors must be considered in future research.

The cognitive-perceptual aspect is a critical element when exploring a behavioral concept such as self-care. In the current literature, two cognitive-perceptual factors: perceived self-efficacy and locus of control have received special attention. It is now thought that a subject's perceived self-efficacy influences behavior patterns to a greater degree than the subject's locus of control. Clearly the addition of cognitive-perceptual factors in future studies of caregiver self-care behavior will provide a more thorough understanding of caregiver self-care.

Statement of the Research Questions

The research questions will be presented along with a brief review of the findings relevant to each question. A discussion of the findings and comparisons with the literature (when possible) will also be included.

Question 1. What are the reported self-care practices of a group of primary caregiver's to Alzheimer's patients?

Question 2. What relationship do selected independent variables have with the dependent variables: caregiver physical, caregiver time-care, caregiver sleep-care, caregiver social-care, caregiver diet-care.

Specifically. How are the following independent variables related to caregiver: physical-care, time-care, sleep-care, social-care and diet-care.

- caregiver age
- caregiver sex
- caregiver education
- caregiver employment
- caregiver relation to Alzheimer's patient
- duration of caregiving
- caregiver health
- caregiver perceived health
- caregiver depression
- caregiver social interaction
- impact of caregiving on caregiver's schedule
- amount of assistance from family and friends

Findings for Research Question 1. The findings concerning the self-care practices of the sample analyzed were presented in Table 5.5. In general the sample of caregivers reported favorable self-care practices and appeared knowledgeable about recommended self-care practices. The data reported in Table 5.5 were unfortunately subject to one problematic source of bias --self-reporting of self-care practices. As noted in Chapter V, some of the self-care questionnaire items may also elicit a socially desirable response. Furthermore, the self-care items used in this study are not part of a recognized scale to measure self-care.

Despite the aforementioned conditions, the data collected compares favorably with self-care data collected on a similar aged non-caregiving sample. Data from the 1985 National Health Interview Survey of Health Promotion and Disease Prevention (Thornberry, Wilson, Golden, 1986) can be used to compare the self-care knowledge and practices of this sample with the self-care knowledge and practices of a national sample of similar aged, non-caregivers. Eleven of the questionnaire items from the 1985 Health Promotion and Disease Prevention Study are similar to questionnaire items used in this study. The Eleven questions are presented below for group comparison. Responses are from non-caregiving subjects 45-64 years old.

1. How often do you eat breakfast?

   62% everyday; 16% sometimes; 21% rarely or never

2. Do you consider yourself overweight, underweight, or just about right?

12% very overweight; 21% somewhat overweight; 23% only a little overweight; 40% about right; 3% underweight

3. On average, how many hours of sleep do you get in a 24 hour period?

   23% less than 7 hours; 67% 7-8 hours; 10% 9 or more hours

4. About how many times a year do you examine your own breasts for lumps? (females only)

   37% 12 or more times; 2% 7-11 times; 32% 2-6 times; 4% once a year; 13% never; 11% don't know how to examine breasts

5. In the past 2 weeks, have you done any of the following exercises, sports, or physically active hobbies?

   41% walking for exercise; 4% jogging or running;
   15% calisthenics or general exercise; 8% biking;
   6% swimming or water exercises.

6. Do you exercise or play sports regularly? 38% yes

7. In the past 2 weeks, on how many days did you drink any alcoholic beverages such as beer, wine, or liquor?

   39% did not drink in past year; 14% none; 27% 1-4 days;
   7% 5-9 days; 13% 10-14 days

The following 3 conditions/activities may or may not affect a person's chances of getting heart disease. After reading each one respond: definitely increases, probably increases, probably does not, or definitely does not, increase a person's chances of getting heart disease.

8. Eating a diet high in animal fat?

   46% definitely increases; 37% probably increases;
   6% does not increase; 5% probably does not increase;
   3% definitely does not increase; 9% don't know/no opinion

9. Family history of heart disease?

   51% definitely increases; 33% probably increases;
   8% does not increase, 5% probably does not increase;
   3% definitely does not increase; 9% don't know/no opinion

10. High Cholestrol?

    58% definitely increases; 29% probably increases;
    4% does not increase; 3% probably does not increase;
    1% definitely does not increase; 9% don't know/no opinion

11. Which one of the following substances in food is most often associated with high blood pressure?

    61% sodium (or salt); 24% cholestrol; 7% sugar; 8% don't know

(Thornberry et al., 1986, pp 1-10)

Using the National Health Interview Survey data of 1985, the sample of caregivers in this study appear to have self-care knowledge and practices quite similar to their non-caregiving contemporaries.

As mentioned earlier, the self-care questionnaire items used in this study have not been previously tested. The lack of established validity and/or reliability for this self-care "scale" produces an inherent weakness in the study results. The findings for research Question 1 of this study could have been "strengthened" by using a valid and reliable research instrument for measuring the concept self-care. Walker, Sechrist and Pender (1987) comment on the lack of scales or instruments to measure self-care knowledge/behavior:

> Despite increasing empirical support for the interrelationship between style of life and health status, there have been few attempts to develop valid and reliable research instruments for measuring life-style as either a global or a health-specific concept.
>
> (p. 76)

Because lifestyle has emerged as an extremely useful construct in the health field, efforts directed toward developing reliable and valid research methods for it are underway.

One recently developed instrument to measure health promoting lifestyle is the Health Promoting Lifestyle Profile

(HPLP), (Walker, Sechrist, Pender, 1987). In an initial psychometric evaluation of the HPLP on 952 adults (average age 39.2 years) the instrument was shown to have sufficient validity and reliability for measuring health promoting components of lifestyle (Walker, Sechrist, Pender, 1987). Perhaps the greatest weakness of the HPLP is the lack of testing the HPLP among various population samples. To assume the HPLP can be utilized with an elderly caregiving sample without an initial evaluation is ludicrous. The HPLP must be tested and /or redefined for the specific population it is to be used with. While showing promise with an adult sample, the HPLP has not been evaluated on any other sample group. It is conceivable that some of the factors and subscales composing the HPLP may not be appropriate for use with an elderly, caregiving population. As explained earlier in the study, it is essential that the components of a healthy lifestyle be clearly understood and appropriately measured if research and ultimately practice concerned with supporting such a lifestyle are to go forward.

Findings for Research Question 2. Research Question 2 was aimed at exploring what relationship selected independent variables had with the dependent variables representing caregiver self-care. Referring back to the conceptual framework developed for this study, (Figure 3) Research Question 2 is a written representation of the conceptual framework. The selected independent variables used in the study are represented by the seven modifying factors in the conceptual framework. The five dependent variables in the study are represented by 'caregiver self-care' in the conceptual model.

It is important to note here that the labels of independent and dependent variables were made for the purposes of statistical analysis rather than to preserve conceptual integrity. As mentioned previously, the seven modifying factors in the conceptual framework correspond to the selected independent variables used in the study. Certainly an argument can be made for the inclusion of more modifying factors or different variables to represent the modifying factors. In future research pertinent to this study, additional factors meriting consideration include caregiver: self-efficacy, locus of control, and developmental status. None of the aforementioned factors were included in this study and remain unknowns in their influence on caregiver self-care.

The findings generated from this study are unique in the sense that no previous studies were found in which the self-care practices of Alzheimer's caregivers were explored. Despite its limitations and methodological weaknesses, this study does represent an initial attempt to provide empirical evidence of the relationship between caregiver self-care and a collection of independent variables.

For the purpose of this study, the 'study findings' will include a discussion of only those independent and dependent variables found to share a 'significant' relationship (F= <.05) in regard to the change in R squared observed in the regression analyses. A large change in R squared indicates that a variable provides unique information about the dependent variable that is not available from the other independent variables in the equation. Referring to Table 5.6, significant (F= <.05) changes in the R squared value are observed in Regression Analysis #1 for dependent variables: time-care, sleep-care and social-care. No significant changes in R squared were observed in Regression Analysis #2. Two significant R squared changes were observed in Regression Analysis #3 in relation to dependent variables physical-care and sleep-care. Each of the 'significant' values is now reviewed separately and in greater depth according to each of the dependent variables in the study.

Physical-Care. Looking across Table 5.6 at regression analysis #1, #2, #3 for the dependent variable physical-care, it is clear that all the independent variables together account for 25% (R squared =.25) of the variance in caregiver physical-care. According to Table 5.6, the largest change in R squared occurred in Regression Analysis #3 where 'Health' is the last independent variable entered in the regression equation. Of the two variables composing the 'Health' variable 'caregiver health problems' is shown in Table 5.7 as contributing more to the change in R squared than 'perceived health'.

Therefore, of all the independent variables in this study 'caregiver health problems' is the variable contributing most to the change in R squared and consequently is the independent variable most closely related to caregiver physical-care. The relationship between a caregiver's health status and their 'physical-care' seems obvious. Nevertheless, based on the results of this study a caregiver's health problems are a variable not to be overlooked when evaluating a caregiver's physical-care (activities centered around physical exercise and maintaining ideal body weight).

Time-Care. Looking across Table 5.6 at regression analyses #1, #2, #3, for dependent variable time-care, it is clear that all the independent variables together account for 50% (R squared = .50) of the variance in dependent variable time-care. The largest R squared change occurred in Regression Analysis #1 and was calculated to be significant (F= <.05). The independent variable producing the largest R squared change in Analysis #1 was 'caregiver depression'(see Table 5.7). Therefore, caregiver depression is the independent variable in this study sharing the closest relationship with the dependent variable time-care. The items composing the time-care variable center on the caregiver taking time for themselves in leisure, sleep and social contact. It is logical to accept the premise that caregiver depression is likely to impact a caregiver's leisure, sleep and social contact. On the basis of these results 'caregiver depression' is a variable that merits assessment when seeking to describe or predict a caregiver's 'time-care'.

Sleep-care. Looking across Table 5.6 at regression analyses #1, #2. #3, for dependent variable sleep-care, it is evident that all the independent variables together account for 45% (R squared= .45) of the variance in the dependent variable sleep-care. Two of the independent variables produced significant changes in R squared: 'caregiver depression' in

Regression Analysis #1 and 'caregiver health' in Regression Analysis #3. On the basis of the results in Table 5.7, 'caregiver depression' shares a closer relationship with 'sleep-care' than 'caregiver health'. Sleep-care is specific to the caregiver's ease achieving sleep, length of sleep, and quality of sleep. The observed relationships of caregiver depression and health to caregiver sleep-care appear reasonable. Levels of depression are known to interfere with sleep patterns and numerous health problems can influence the quality and quantity of sleep.

Social-Care. Looking across Table 5.6 at Regression Analyses #1, #2, #3, for dependent variable social-care, it is evident that all the independent variables together account for 39% (R squared= .39) of the variance in dependent variable 'social-care'. The largest and only significant change in R squared occurred in Regression Analysis #1 where 'caregiver depression' was the last variable to be entered (see Table 5.7). Based on the results of Analysis #1 it may be said that a caregiver's proclivity to be social is related to the caregiver's level of depression. The aforementioned relationship makes logical sense and is supported indirectly through a study by George and Gwyther (1984). George and Gwyther (1984) investigated cross-sectional data on Alzheimer's caregivers' well-being and found the dimensions of mental health and social activity most adversely affected as a result of caregiving.

Diet-Care. Looking across Table 5.6 at Regression Analyses #1, #2, #3, for dependent variable diet-care, it is evident that all the independent variables together accounted for only 8% (R squared= .08) of the variance in the dependent variable diet-care. None of the independent variables produced a significant change in R squared in relation to diet-care (see Table 5.7) and the reasons for this were discussed in Chapter III.

In sum, the independent variable 'caregiver depression' has been shown to have a relationship with three of the five dependent variables in this study. The limited amount of research currently available on caregiver depression is evidence of a need for more research. A study by Kahan et al. (1985) indicated caregiver depression may be lessened by an intervention that offers practical knowledge about Alzheimer's Disease within a supportive environment where the caregiver can ask questions and discuss individual problems. Recognizing and intervening to alleviate caregiver depression may prove to be a first step on the way to improving caregiver self-care.

The other independent variable showing a relationship with two of the five dependent self-care variables is 'caregiver health'. Between these variables is a sort of 'what came first' phenomena -- good health or good self-care practices? Regardless, efforts to support the caregiver's self-care practices should in turn influence the caregiver's health status and vice versa.

The findings pertinent to Research Question 1 and 2 were presented in the preceding section. Unfortunately interpretation of the findings is limited by the lack of research in this area and generalization of the findings is limited by the study design. Perhaps the most functional purpose of the study findings is the information gained on using these self-care questionnaire items as an instrument or scale for measuring caregiver self-care. The remainder of the Chapter is devoted to a discussion of the implications of these findings for nursing practice, education and research.

Implications for Nursing Practice

This section will be a description of the implications for nursing practice based on the research focusing on the role of the Clinical Nurse Specialist (CNS). To a degree, the observation made by Robinson in 1986 -- that other disciplines have identified the need for nursing's role in caregiving, yet nurses have not written a great deal on their role in caregiving -- remains true. Research into caregiver health and welfare, while achieving overall agreement that the prevalence of 'burden' is higher among carers than the general population, has yet to identify ways that it (burden) can be alleviated. Research on the experiences of the informal carer must raise questions about the present organization and delivery of nursing care. Are there specific nursing interventions which would not only alleviate the 'burden' of the caregiver, but also anticipate needs and meet them?

Because Alzheimer's Disease is currently a condition of management rather than treatment or cure, nurses in advanced practice are ideally suited to provide leadership in this management. The need to 'manage' the caregiver as well as the patient is being recognized as the demand for viable, informal carers becomes essential in providing affordable long-term care for Alzheimer's patients.

To present a discussion of the implications of this study in relation to advanced nursing practice, the study findings are discussed in relation to the fourteen role characteristics of the clinical nurse specialist (Michigan State University College of Nursing, 1985-86). The first role of the clinical nurse specialist is that of Assessor. In regard to this study, the CNS is responsible for assessing the modifying factors as experienced by the caregiver in addition to an assessment of the caregiver's self-care. The assessment process is influenced by the CNS role of Researcher since data gathering is research based. Based on the findings from this study, the CNS should pay particular attention to the caregiver's health status and signs of symptoms of caregiver depression, as variables likely to influence the caregiver's self-care.

After the assessment data is gathered, a nursing diagnosis should be identified. Nursing diagnoses should include the etiology of the problem (Gorden, 1984). Based on the model for this study, the diagnosis of 'self-care deficit' would be specified at a level of 'none' to 'total'. Expanding the modifying factors of the conceptual framework would allow the CNS to consider and/or rule out a greater number of possible etiologies for the self-care deficit. The findings from this study show the relative strength or weakness of the relationships between the independent variables (modifying factors) and caregiver self-care. Deleting variables showing a weak relationship to self-care and adding variables not yet tested, will further refine the CNS's continuous assessment, critical thinking and judgement in discovering the etiology of the caregiver's self-care deficit.

As a Planner, the CNS should apply the additional roles of Change Agent, Collaborator, Educator and Counselor. Planning should include the caregiver and CNS mutually developing self-care goals and strategies to meet the goals. As a change agent and educator, the CNS should assist the caregiver in recognizing that successful self-care changes require effort over an extended period to achieve the greatest benefit. In short, self-care maintenance is a life-long commitment. It is important for the CNS as counselor to assist the caregiver with planning strategies that are realistic for supporting or improving the caregiver's self-care within the context of their current lifestyle. Collaboration is based on mutual exploration and implies joint responsibility for the development and support of goals related to self-care. The CNS can provide the caregiver examples of ways to improve self-care based on the assessment data and the caregiver's individual obstacles and/or resources.

As Clinician, the CNS formulates the nursing diagnosis and provides the necessary care, based on sound theory and advanced clinical judgement, to promote caregiver participation in self-care behavior. The CNS may find himself or herself as a member on a multidisciplinary team. In a team approach to the care of the caregiver/Alzheimer's patient dyad, the CNS can function as team Coordinator. As coordinator, the CNS has the responsibility of coordinating multiple disciplines to meet the needs of the caregiver identified by the team members. Recognized for his or her nursing expertise, the CNS can serve as Consultant to other health professionals as well as lay groups, by providing information/advice on maintaining caregiver health and well-being.

To serve as a Role Model, the caregiver must perceive the nurse has behavior or health practices worthy of emulating. It would therefore be inappropriate for advance practice nurses who do not embody the beliefs and practices of health promotion, to provide care to caregivers desiring to restructure their lifestyle by improving their self-care.

In the role of Evaluator, the CNS must be prepared to provide sound documentation of the effect of the CNS on nursing practice and patient care. That is, the CNS must use standards of practice to appraise the effectiveness of his or her role in addition to utilizing an evaluation process to track the performance of the caregiver. It is important to note that the evaluation process utilized between the CNS and the caregiver should be mutually determined and the results of the evaluation process mutually explored to enhance caregiver accountability in the evaluation process.

Perhaps most pertinent to the focus of this study is the role characteristic, Client Advocate. As defined in the Michigan

State University College of Nursing Graduate Student Handbook (1985-86) client advocate denotes, "One who works to promote a transfer of responsibility to the client by creating a climate of mutuality in which the nurse assists the client in exercising his/her rights and in improving self-care abilities" (p. 22). Advocacy for the Alzheimer's caregiver is a timely issue and an issue ripe for nursing leadership. The CNS as a <u>Leader</u> in the nursing profession has the ability to impact health care systems as well as political systems to achieve the health care goals of the Nation.

There are many arenas in which the role characteristics of the CNS may be utilized. Nevertheless, the optimal setting for the CNS is the primary care arena. In the primary care setting the CNS has the opportunity to develop a proficiency in the greatest number of role characteristics. Case management of an Alzheimer's caregiver in the primary care setting could conceivably necessitate the CNS to function in the following roles: clinician, assessor, planner, educator, counselor, collaborator, change agent, coordinator, role model, evaluator and client advocate.

Due to the complex management issues that arise in relation to Alzheimer's cases; plus the chronic nature of the disease, primary care settings are a likely site of healthcare for the Alzheimer's caregiver. The CNS must be cognizant of the "double agenda" lived by most caregivers and plan interventions that are realistic. Acting as the primary provider, the CNS can insure

that the Alzheimer's caregiver receives interdisciplinary evaluation without getting lost in the "healthcare shuffle".

In sum, the clinical nurse specialist has the necessary skills, advanced knowledge, and clinical judgement, to provide assistance to Alzheimer's caregivers in the area of self-care assessment, modification and/or maintenance. The clinical nurse specialist, as a Master's prepared professional, can contribute to the body of nursing knowledge by applying research findings and established theory while functioning in the aforementioned role characteristics. The application of research findings to the care and management of Alzheimer's caregivers has some implications for nursing education. Those concerns are addressed in the following section.

Implications for Nursing Education

Nurses, as the largest group of health professionals, have more contact with Alzheimer's caregivers than any other health care provider. As a result, the nurse has more opportunity to assess and/or intervene in the caregiver's self-care behaviors.

While most nursing education programs address the pathophysiology and treatment of disease states, Alzheimer's Disease requires the largest focus be placed on management. All nurses should be informed about the complexity of managing the caregiver/patient dyad, especially in regard to the caregiver's self-care and well-being. Teaching nurses about the Health Promotion Model (Pender, 1987) can promote a degree of understanding of the factors that must be assessed and addressed in utilizing self-care as a means to support viability of the long-term caregiver. The ability of the nurse, at any level of education, to accurately assess, plan, implement and evaluate a program of self-care, depends upon the nurse's awareness of the multiplicity of factors that contribute to the caregiver's self-care agency.

Orem's (1985) self-care deficit theory of nursing links nursing practice to a theory of self-care. Pender's (1987) health promotion model links self-care to a conceptual framework of factors hypothesized to influence self-care. Together the two models provide a theoretical base for nursing's role in assessing, facilitating and monitoring an individual's self-care ability. The Orem and Pender models should, therefore, be introduced at all levels of nursing education.

Due to the complexity of nursing roles and the Alzheimer's patient/caregiver relationship, nurses who are primary care providers to Alzheimer's caregivers should be prepared at the graduate level. The CNS in ambulatory, primary care settings should be prepared to collect data to identify the self-care needs of caregivers and factors inhibiting or facilitating caregiver self-care. As case managers, the CNS will coordinate the caregivers care utilizing other health professionals as needed to develop and execute intervention strategies. These behaviors require advanced educational preparation in a research based program.

Education in the appropriate collection, intervention and evaluation of caregiver self-care data would not only contribute to the body of nursing knowledge, it would provide a mechanism to demonstrate effectiveness in meeting measurable outcomes for long-term caregiver viability. Caregiver self-care deficits contribute to health care costs by increasing the potential for caregiver illness which in turn jeopardizes the carers caregiving role and necessitates a costly move to institutional care for the Alzheimer's patient. Nurses who are educationally prepared to foster caregiver self-care can contribute to cost containment of long-term care and to the health of the nation's caregivers. If more value were placed on supporting the informal carer, perhaps more research dollars would be available to discover the cause and treatment of Alzheimer's Disease.

Implications for Future Research

The problems associated with studies of caregiver self-care or well-being have been discussed throughout this paper. Despite the general lack of research in this area, inconsistencies in definitions and measurements of concepts related to caregiver self-care are serious short-comings in the research to date. The difficulties in comparing results is related to the inconsistencies, not only with regard to the factors thought to influence caregiver self-care, but inconsistencies in the measures of caregiver self-care.

A number of recommendations for future research can be suggested based on this study. The recommendations are based on the limitations suggested in interpreting the findings as well as limitations found in other caregiver self-care research. In order to obtain data necessary for effective, research-based practice, it is imperative that further research be conducted to determine factors contributing to, or detracting from, the caregiver's participation in self-care behaviors. To obtain the aforementioned data the following activities are necessary.

The concepts of Pender's (1987) health promotion model should be defined for the caregiving environment and these definitions should be used consistently among researchers. Instruments to measure each of the concepts (in Pender's model) should also be designed and vigorously tested for reliability and validity before use. Once reliable measures of the concepts are found, the measures should be used repeatedly so that research findings can be compared. It is recommended, based on this study, the cognitive-perceptual factors from Pender's (1987) health promotion model (see Figure 2.) be included in an expanded conceptual model to measure the likelihood of caregiver participation in self-care and/or health promoting behaviors.

The definitions and measurements of self-care must also be consistent in future research so results can be compared. The Health-Promoting Lifestyle Profile (HPLP) developed by Walker, Sechrist and Pender (1987) offers sufficient validity and reliability for use by researchers who wish to:

> - describe the health-promoting component of lifestyle in various populations;
>
> - to explore correlates or determinants of health-promoting life-style;
>
> - to measure changes in health-promoting lifestyle as a result of interventions.
>
> (p. 80)

The authors of the HPLP stress the point that further development and evaluation of the HPLP is warranted. Additional studies using the HPLP with populations representing various states of health and illness as well as various socio-economic levels and diverse cultural backgrounds are needed to further evaluate construct validity and establish norms. It is recommended, based on this study, that a recognized instrument (such as the HPLP) be tested on a sample of Alzheimer's caregivers. Only with reliable and valid instruments, can accurate conclusions be reached and effective interventions be developed.

Focusing on the procedures and methods used in this study a number of recommendations for future studies can be made. First, to allow for generalization of findings to the larger caregiver population, the conditions of random sampling must prevail in future research of caregiver self-care. Second, experimental designs (random sample, experimental/control groups) must be employed in future studies of caregiver self-care behaviors. True experiments are the most powerful method available to researchers for testing cause and effect relationships between variables (Polit and Hungler, 1983). Third, it is recommended that experimental nursing intervention studies be conducted. The nursing intervention should specifically focus on fostering caregiver participation in self-care. The caregivers in such a study should be followed across time (longitudinal study) to determine if compliance with self-care behaviors was maintained and what effect this had on caregiver viability. Longitudinal studies are especially important to studies of self-care and/or health promotion. Such studies would provide information related to the amount and type of monitoring needed to maintain the caregiver's participation in self-care behaviors.

Lastly, as mentioned in Chapter III, the majority of the studies reviewed for this paper made recommendations that must be tested before they can be considered "best solutions". Any recommendation put forth should be regarded as tentative, pending empirical evidence to support the validity of the proposed recommendation/intervention. In addition, when testing intervention strategies suggested in the literature, the researcher must account for the perspective of both the caregiver and Alzheimer's patient, prior to endorsing the proposed intervention.

Based on the findings from this study, the research questions addressed need further exploration. It is also imperative that other questions concerning caregiver self-care be considered in future research. Such questions include: How do providers perceive the effectiveness of self-care in maintaining caregiver viability? What are providers currently doing in their practices to assess, intervene and then monitor caregiver self-care? What other factors and or variables are important to self-care activities? Who are the most appropriate providers to organize and execute a strategy to foster caregiver participation in self-care? Answers to these questions can be used to provide education to all providers caring for caregivers to at least maximize the effectiveness of self-care as a means of maintaining long-term viability of the Alzheimer's caregiver.

Summary

There are results from this study that indicate caregiver depression and caregiver health are related to components of caregiver self-care. Although there was no evidence from this study to support a relationship between the other study variables and self-care, measurement problems and the nature of selected study variables may have contributed to the lack of observed relationships. Much of the information from this study is not supported in the literature due to a dearth of research on caregiver self-care. Clearly, there is a need for additional studies from which result comparisons can be made.

Pender's (1987) health promotion model along with Orem's (1985) theory of self-care provided a framework for this study representing factors hypothesized to influence the caregiver's level of self-care. In the future, the framework must be reworked or expanded to test nursing interventions hypothesized to promote caregiver viability through the support of caregiver self-care.

The information in Chapter VI includes the major findings from this study. A description and analysis of the research sample was presented and compared to those of other studies. Findings from this study were discussed and recommendations and implications for future nursing practice, education and research presented.

APPENDICES

APPENDIX A

MICHIGAN STATE UNIVERSITY

UNIVERSITY COMMITTEE ON RESEARCH INVOLVING
HUMAN SUBJECTS (UCRIHS)
206 BERKEY HALL
(517) 353-9738

EAST LANSING • MICHIGAN • 48824-1111

September 30, 1988

IRB# 88-344

Kathleen Powers-LaMoe
114 F. Washington Road
West Point, NY 10996

Dear Ms. Powers-LaMoe:

Subject: "SELF-CARE AND THE RELATIONSHIP OF SELECTED VARIABLES TO SELF-CARE: AMONG PRIMARY CAREGIVERS OF ALZHEIMER'S DISEASE PATIENTS **IRB# 88-344**"

The above project is exempt from full UCRIHS review. The proposed research protocol has been reviewed by another committee member. The rights and welfare of human subjects appear to be protected and you have approval to conduct the research.

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 one month prior to September 26, 1989.

Any changes in procedures involving human subjects must be reviewed by 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 my attention. If I can be of any future help, please do not hesitate to let me know.

Sincerely,

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

JKH/sar

cc: B. Given

APPENDIX B

Charles W. Given
279-40-6436

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 with Alzheimer's disease affects the individual providing the care. Over the next year, caregivers, will be interviewed by a member of the research staff three times (at intake, at the end of the intervention, and six months after the intervention). Further, each caregiver will be asked to keep a diary. You will be asked to record your feelings and reactions to caregiving. Each interview will take approximately one hour to complete. If you are willing to participate, please sign the following statement.

1. I have freely consented to take part in a study of caregivers conducted by the College of Nursing and 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 if I withdraw from the study after originally agreeing to participate, the amount and quality of service provided me by my private physician and regular health care will not change. 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 that 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 resonses may add to the understanding of health care professionals of the experience of being responsible for an older family member.

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

Signed __________________________________ Date ____________________________
(signature of caregiver)

7/25/85
jy

APPENDIX C

Questionnaire Items From Original Data Collection Instrument

Caregiver Demographic Questionnaire Items:

1. What is your date of birth? Month/Date/Year

2. How far did you go in school?
    - (1) grade school or less
    - (2) some high school
    - (3) high school
    - (4) some college or tech. training
    - (5) college
    - (6) grad. or professional school

3. What is your marital status?
    - (1) single, never married
    - (2) married
    - (3) widowed
    - (4) separated
    - (5) divorced
    - (6) other

4. Caregiver's sex?
    - (1) male
    - (2) female

5. What is your relationship with the Alzheimer's patient?
    - (1) spouse
    - (2) child
    - (3) daughter/son in law
    - (4) brother/sister in law
    - (5) other

6. Are you currently employed?
    - (1) yes
    - (2) no

7. How many years ago did the Alzheimer's patient's symptoms or problems begin?
    - (1)"actual number of years"

Caregiver Perceived Health (Subjective) Questionnaire Item:

1. How would you rate your overall physical health at the present time?
    - (1) excellent
    - (2) good
    - (3) fair
    - (2) poor
    - (1) no answer

Caregiver Health (Objective) Questionnaire Items:

. . . now I'm going to read you a list of illnesses. Please answer "YES" if you have been told by a health care professional that you currently have this illness and "NO" if you have not been told you have this health problem.

1. Arthritis
    - (1) yes
    - (2) no
    - (9) no answer
2. Glaucoma or Cataracts
    - (1) yes
    - (2) no
    - (9) no answer
3. Emphysema or Chronic Bronchitis
    - (1) yes
    - (2) no
    - (9) no answer
4. High Blood Pressure
    - (1) yes
    - (2) no
    - (9) no answer
5. Heart Trouble
    - (1) yes
    - (2) no
    - (9) no answer
6. Diabetes
    - (1) yes
    - (2) no
    - (9) no answer
7. Stomach or Intestinal or Gall Bladder Problems
    - (1) yes
    - (2) no
    - (9) no answer
8. Kidney or Urinary Track Disease
    - (1) yes
    - (2) no
    - (9) no answer
9. Cancer or Leukemia
    - (1) yes
    - (2) no
    - (9) no answer
10. Effects from a Stroke
    - (1) yes
    - (2) no
    - (9) no answer
11. Parkinson's Disease
    - (1) yes
    - (2) no
    - (9) no answer

12. Nervous Disorders (1) yes
(2) no
(9) no answer

13. Broken Hip (1) yes
(2) no
(9) no answer

14. Memory Problems (1) yes
(2) no
(9) no answer

15. Prostate Trouble (males only) (1) yes
(2) no
(9) no answer

Caregiver Depression Questionnaire Items:

During the past month, how much of the time . . .

Response choices for all
depression questions ----------> (1) rarely/none of the time
(2) some of the time
(3) most of the time
(4) almost all of the time
(9) no answer

1. Were you bothered by things that don't usually bother you?

2. Have you not felt like eating; or had a poor appetite?

3. Have you felt that you could not shake off the blues, even with the help from family or friends?

4. Have you felt that you were just as good as other people?

5. Have you had trouble keeping your mind on what you were doing?

6. Have you felt depressed?

7. Have you felt that everything you did was an effort?

8. Have you felt hopeful about the future?

9. Have you thought your life has been a failure?

10. Have you felt tearful?

11. Has your sleep been restless?

12. Were you happy?

13. Have you talked less than usual?

14. Have you felt lonely?

15. Were people unfriendly?

16. Have you enjoyed life?

17. Have you had crying spells?

18. Have you felt sad?

19. Have you felt that people disliked you?

20. Could you not get "going"?

<u>Questionnaire Items Used to Measure the Impact of Caregiving on the Caregiver's Schedule:</u>

Response choices for all impact on schedule questions:

(1) strongly disagree
(2) disagree
(3) neither agree nor disagree
(4) agree
(5) strongly agree

1. My activities are centered around care for ________.

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

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

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

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

<u>Caregiver Social Interaction Questionnaire Items:</u>

1. How often is caregiver with friends and relatives?

(1) everyday
(2) several days per/week
(3) once a week
(4) 2-3X per week
(5) once per month
(6) 5-10X per year
(7) less than 5X per year

2. How often are friends at caregiver's home?

(1) everyday
(2) several days per/week
(3) once a week
(4) 2-3X per month
(5) once per month
(6) not at all in past month

3. How often does caregiver visit at friend's home?

(1) everyday
(2) several days per/week
(3) once a week
(4) 2-3X per month
(5) once per month
(6) not at all in past month

4. How often does caregiver telephone family/friends?

(1) everyday
(2) several days per/week
(3) once a week
(4) 2-3X per month
(5) once per month
(6) not at all in past month

5. How often does caregiver write friend/relative?

(1) everyday
(2) several days per/week
(3) once a week
(4) 2-3X per month
(5) once per month
(6) not at all in past month

6. How often does caregiver attend religious services?

(1) everyday
(2) several days per/week
(3) once a week
(4) 2-3X per month
(5) once per month
(6) not at all in past month

Questionnaire Items used to Measure the Caregiver's Assistance from Family and Friends:

Caregivers were asked, "how often in the past three months have family of friends . . . "

1. Checked regularly on you?

2. Helped you with routine chores?

3. Helped you with heavy cleaning?

4. Helped you with legal or money matters?

5. Helped you with transportation?

6. Taken care of your relative so you could get away?

7. Made meals for you?

The numerical values reported by the caregiver on each of the seven questions above were summed for a combined score representing each individual caregiver.

Questionnaire Items used to Assess Caregiver Self-Care (i.e. Physical-Care, Time-Care, Sleep-Care, Social-Care, Diet-Care):

Response choices for all
self-care questions: (1) never do this
(2) do this occasionally
(3) regularly do this

1. Exercise 15-30 min. 3 times per/week.

2. Preform leisure activity for fitness.

3. Maintain ideal body weight.

4. Eat a variety of foods.

5. Limit fat and cholesterol.

6. Limit refined sugar.

7. Limit amount of salt.

8. Eat breakfast daily.

9. Drink more than 3 cups of caffeinated beverages per/day.

10. Follow medication label directions.

11. Know what medications are for.

12. Take drugs without Dr.'s prescription.

13. Sleep 6 - 8 hours per/night.

14. Have uninterrupted sleep.

15. Sleep easily without medications.

16. Drink 6-8 cups of water per/day.

17. Take laxatives.

18. Observe body for cancer signs.

19. Take time for myself daily.

20. Report unusual signs/symptoms promptly.

21. In normal day walk one mile.

22. Use alcohol and/or drugs when stressed.

23. Go out with friends daily.

REFERENCES

REFERENCES

ADRDA (1987). Fact sheet on Alzheimer's disease. (Available from Alzheimer's Disease and Related Disorders Association, Inc. 70 East Lake Street Suite 600 Chicago, Il. 60601 Phone 312-853-3060 Form: Ed200Z -7/87.

Barnes, R.F., Raskind, M.A., Scott, M., & Murphy, C. (1981) Problems of families caring for Alzheimer's patients: Use of a support group. Journal of the American Geriatrics Society, 29(2), 80-85.

Belloc, N.B., and Breslow, L. (1972). Relationship of physical health status and health practices. Preventive Medicine 1, 409-421.

Bird, T.D., Stranahan, B.S., Sumi, S.M., Raskind, M. (1983). Alzheimer's disease: Choline acetyltransferase activity in brain tissue from clinical and pathological subgroups. Annals of Neurology, (14), 284-93.

Bondareff, W. (1983). On the relationship between age and Alzheimer's disease. Lancet, (1), 1447.

Brody, E. (1981). Women in the middle: And family help to older people. The Gerontologist, 21, 471-480.

Burgess, A.W., and Lazare, A. (1976). Psychiatric nursing in the hospital and the community (2nd ed.). Englewood Cliffs, New Jersey: Prentice-Hall, Inc.

Cantor, M. (1983). Strain among caregivers: A study of experience in the United States. The Gerontologist, 23(6), 597-604.

Carnevali, D.L., and Patrick, M. (1979). Nursing Management for the Elderly. Philadelphia, J.B. Lippincott Company.

Caserta, M.S., Lund, D.A., Wright, S.D., Redburn, D.E. (1987) Caregivers to dementia patients: The utilization of community services. The Gerontologist, 27 (2), 209-214.

Charlesworth, A., Wilkin, D., and Dune, A. (1983). Carers and services: A comparison of men and women caring for dependent elderly people. Department of Psychiatry and Community Medicine, University of Manchester.

Chenoweth, B., and Spencer, B. (1986). Dementia: The experience of family caregivers. The Gerontologist, 26(3), 267-272.

Chestnut, C. (Ed.). (1987). Reflections: A quarterly publication by, Sigma Theta Tau International, International honor society of nursing. (13)4, Winter, 1987.

Christiansen, K.E. (1981). The determinants of health promoting behavior. Unpublished doctoral dissertation, Rush University, Chicago. Clark, N.M. and Rakowski, W. (1983). Family caregivers of older adults: Improving helping skills. The Gerontologist, 23(6), 637-642.

Cobb, S. (1976). Social support as a moderator of life stress. Psychosomatic Medicine, 38, 300-314. Cohen, D., and Eisdorfer, D. (1986). The loss of self: A family resource for the care of Alzheimer's disease and related disorders. New York: W.W. Norton and Company.

Colerick, E.J. and George, L.K. (1986). Predictors of institutionalization among caregivers of patients with Alzheimer's disease. The Journal of the American Geriatrics Society, 34, 493-498.

Cowling, W.R., and Campbell, V.G. (1986). Health concerns of aging men. Nursing Clinics of North America, 21 (1), 75-83.

Deimling, G.T., and Bass, D.M. (1986). Symptoms of mental impairment among elderly adults and their effects on family caregivers. Journal of Gerontology, 41(6) 778-784.

Dimond, M., and Jones, S.L. (1983). Social support: A review and theoretical integration. In P.L. Chinn (Ed.), Advances in nursing theory development (pp. 235-249). Rockville, MD: Aspen Systems Corp.

Dishman, R.K., Sallis, J.F., and Orenstein, D.R. (1985). The determinants of physical activity and exercise. Public Health Reports, 100(2) 158-171. Dunn, H.L. (1980). High level wellness. Thorofare, N.J.: Charles B. Slack, p.4.

Dunn, C.R., and Gallaway, C. (1986). Mental health of the caregiver: Increasing caregiver effectiveness. Caring, July, 37-42.

Elias, J.W., Hutton, J.T., Bratt, A.H., Miller, B.A., Weinstein, L.A. (1987). Caretaker coping and Alzheimer's patient decline. Texas Medicine, 83, 46-47.

Fengler, A., and Goodrich, N. (1979). Wives of elderly disabled men: The hidden patients. The Gerontologist, 19(2), 35-44.

George, L.K., and Gwyther, L.P. (1984). Family caregivers of Alzheimer's patients: Correlates of burden and the impact of self-help groups. From the Center for the Study of Aging and Human Development. Durham, NC: Duke University.

George, L.K., and Gwyther, L.P. (1986) Caregiver well-being: A multidimensional examination of family caregivers of demented adults. The Gerontologist, 26(3), 253-259.

Gilhooly, M.L.M. (1984). The impact of caregiving on caregivers: Factors associated with the psychological well-being of people supporting a dementing relative in the community. British Journal of Medical Psychology, 57, 35-44.

Given, C.W., and Collins, C. (1986). The impact of Alzheimer's disease on family caregivers. 2R01MH41766, Unpublished manuscript.

Given, C.W., and Collins, C. (1987). Addendum to 2R01MH41766, The impact of Alzheimer's disease on family caregivers. Unpublished manuscript.

Goldman, L.S., and Luchins, D.J. (1984). Depression in the spouses of demented patients: Clinical and research reports. American Journal of Psychiatry, 141(11), 1467-1468.

Goldstein, V., Regnery, G., and Wellin, E. (1981). Caretaker role fatigue. Nursing Outlook, 29(1), 24-30.

Goodman, C. (1986). Research on the informal carer: A selected literature review. Journal of Advanced Nursing, 11, 705-712.

Gordon, M. (1982). Nursing diagnosis: Process and application. New York: McGraw-Hill Book Company.

Grad, J., and Sainsbury, P. (1963). Mental illness and the family. Lancet, 1, 544-547.

Gwyther, L.P., and George, L.K. (1986). Caregivers for dementia patients: Complex determinants of well-being and burden; symposium. The Gerontologist, 26(3), 245-247.

Gwyther, L.P., and Matteson, M.A. (1983). Care for the caregivers. Journal of Gerontological Nursing, 9(1), 93-95, 110.

Haley, W.E. (1983). A family behavioral approach to the treatment of the cognitively impaired elderly. The Gerontologist, 23(1), 18-20.

Haley, W.E. (1986). Health and psychological consequences of home care of dementia patients on family caregivers: Assessment and intervention. From the American Association of Retired Persons (AARP) Andrus foundation. National Gerontology Resource Center, 1909 K Street, N.W. Washington, D.C. 20049, Room 600.

Haveven, T. (1980). Main themes of mini-conferences from a historical perspective. Proceedings from the 106th Annual Forum of the National Conference on Social Welfare. New York: Columbia University Press.

Hoyman, H. (1975). Models of human nature and their impact on health education. Nursing Digest, 3(5), 37-40.

Hubbard, P., Muhlenkamp, A.F., Brown, N. (1984). The relationship between social support and self-care practices. Nursing Research, 33(5), 266-270.

Jenkins, T.S., Parham, I.A., Jenkins, L.R. (1985). Alzheimer's disease: Caregivers' perceptions of burden. Journal of Applied Gerontology, 4(2), 40-57.

Johnson, C.L. (1983). Dyadic family relations and social support. The Gerontologist, 23, 377-383.

Johnson, C.L., and Catalano, D.J. (1983). A longitudinal study of family supports to impaired elderly. The Gerontologist, 23(6), 612-618.

Kahan, J., Kemp, B., Staples, F.R., Brummel-Smith, K. (1985). Decreasing the burden in families caring for a relative with a dementing illness. Journal of the American Geriatrics Society, 33(10), 664-670.

Lampe, T.H. (1987). The nature of Alzheimer's disease. In K. O'Connor and J. Prothero (Eds.), The Alzheimer's caregiver: Strategies for support. University of Washington Press: Seattle.

LaVorgna, D. (1979). Group treatments for wives of patients with Alzheimer's disease. Social Work in Health Care, 5(2), 219-221.

Levin, E. (1983). Research on carers: Supporting the informal carers, Report of a Day Conference. DHSS, London.

Lidoff, L. (1985). Support for family caregivers of the elderly: Highlights of a national symposium. Washington, D.C.: National Council on the Aging, Inc.

Mace, N.L., Rabins, P.V. (1981). The 36-hour day: A family guide to caring for persons with Alzheimer's disease, related dementing illnesses, and memory loss in later life. Baltimore: The Johns Hopkins University Press.

Machin, D. (1980). A survey of the behavior of the elderly and their supporters at home. A thesis presented for the degree of Master of Science, University of Birmingham.

McElmurry, B.J., and LiBrizzi, S.J. (1986). The health of older women. Nursing Clinics of North America, 21(1), 161-171.

Metzner, H.L., Carman, W.J., and House, J. (1983). Health practices, risk factors, and chronic disease in Tecumsen. Preventive Medicine 21, 491-507.

Montgomery, R., Gonyea, J., and Hooyman, N. (1985, January). Caregiving and the experience of subjective and objective burden. Family Relations, 34(1), 19-26.

Morycz, R. (1980). An exploration of senile dementia and family burden. Clinical Social Work Journal, 8(1), 16-27.

Morycz, R.K. (1985). Caregiving strain and the desire to institutionalize family members with Alzheimer's disease. Research on Aging, 7(3), 329-361.

Murray, R., Nolan, N., Leonard, B., Zentner, J. (1979). Basic considerations in health and illness. In R.B., Murray and J.P., Zentner (Eds.), Nursing concepts for health promotion (2nd ed.). (p. 5). Englewood Cliffs, NJ: Prentice-Hall, Inc.

Newbigging, K. (1981). A ripe old age: An investigation of relatives of elderly dependents with dementia. The report of an inquiry submitted in part fulfillment of the requirements for The British Psychological Society Diploma in Clinical Psychology.

O'Connor, K. (1987). Introduction. In K. O'Connor and J. Prothero (Eds.), The Alzheimer's caregiver: Strategies for support (pp. vii-x). University of Washington Press: Seattle.

Orem, D.E. (1985). Nursing: Concepts of practice (3rd ed.). New York: McGraw-Hill Book Company.

Pagel, M.D., Becker, J., Coppel, D.B. (1985). Loss of control, self-blame, and depression: An investigation of spouse caregivers of Alzheimer's disease patients. Journal of Abnormal Psychology, 94(2), 169-182.

Palmore, E., and Luikart, C. (1972). Health and social factors related to life satisfaction. Journal of Health and Social Behavior, 13, 68-80. Patrick, D.L., Bush, J.W., and Chen, M.M. (1973). Toward an operational definition of health. Journal of Health and Social Behavior, 14(6).

Pender, N.J., Stromberg, M.F., Walker, S.N., Sechrist, K.R. (1986). Health-promoting behavior: testing a proposed model. NIH, USPHS Grant No. P01NR01121. Unpublished manuscript. Pender, N.J., and Pender, A.R. (1986). Attitudes, subjective norms, and intentions to engage in health behaviors. Nursing Research, 35(1), 15-18.

Pender, N.J. (1987). Health promotion in nursing practice (2nd ed.). Norwalk, Connecticut: Appleton and Lange.

Poulshock, S.W., and Deimling, G.T. (1984). Families caring for elders in residence: Issues in the measurement of burden. Journal of Gerontology, 39(2), 230-239.

Pratt, C.C., Schmall, V.L., Wright, S., and Cleland, M. (1985). Burden and coping strategies of caregivers to Alzheimer's patients. Family Relations, 34(1), 27-33.

Pratt, C., Wright, S., Schmall, V. (1987). Burden, coping and health status: A comparison of family caregivers to community dwelling and institutionalized Alzheimer patients. Gerontological Social Work with Families, 10(1-2), 99-112.

Rabins, P.V., Mace, N.L., and Lucas, M.J. (1982). The impact of dementia on the family. JAMA, 248, 333-335.

Reed, W.L. (1983). Physical health status as a consequence of health practices. Preventive Medicine 1, 409-421.

Robinson, K. (1986). Older women and caregiving. Nursing Success Today, 3(10), 28-33.

Scott, J.P., McKenzie, P.N., Slack, D., Hutton, T.J. (1987). The role of coping behaviors for primary caregivers of Alzheimer's patients. Texas Medicine, 83, 48-50.

Scott, J.P., Roberto, K.A., Hutton, J.T. (1986). Families of Alzheimer's victims: Family support to the caregivers. The American Geriatrics Society, 34, 348-354.

Shanas, E. (1979). The family as a social support system in old age. The Gerontologist, 19, 169-175. (a)

Sheldon, F. (1982). Supporting the supporters: Working with the relatives of patients with dementia. Age and Aging, 11, 184-188.

Soldo, B. and Myllyluoma, J. (1983). Caregivers who live with dependent elderly. *The Gerontologist*, *23*(6), 605-655.

Staff. (1987, Summer, Vol. 22, No. 2). A series, America's great disablers, this issue: Alzheimer's disease. *Perspective, The Blue Cross and Blue Shield Magazine*, p.p. 9-18.

Steiger, N.J., and Lipson, J.G. (1985). *Self-care nursing: Theory and practice*. Bowie, MD: Robert Brady, p. 12.

Troll, L.E. (1971). The family of later life: A decade review. *Journal of Marriage and the Family*, 33, 263-290.

U.S. Department of Health, Education, and Welfare. (1979). *Healthy people: The surgeon general's report on health promotion and disease prevention*. (DHEW Publ. (PHS) No. 79-55-71). Washington, DC: U.S. Government Printing Office.

U.S. Department of Health and Human Services. (1987). *The Dementias Hope Through Research*. (Available from Office of Scientific and Health Reports, National Institute of Neurological and Communicative Disorders and Stroke, National Institutes of Health, Building 31, Room 8A-06, Bethesda, MD 20205.

Weekes, D.P. (1986). Theory-free observation: Fact of fantasy? In P.L. Chinn (Ed.), *Nursing research methodology: Issues and implementation* (p. 19). Rockville, Maryland: Aspen Publishers, Inc. Wiley, J.A., and Camacho, T.C. (1980). Life-style and future health: Evidence from the Alameda county study. *Preventive Medicine 9*, 1-21.

Weiss, I.K., Nagel, C.L., Aronson, M.K. (1986). Applicability of Depression Scales to the Old Old Person. *Journal of the American Geriatrics Society*, *34*(3), 215-218.

Williams-Schroeder, M.L. (1984). Meeting the needs of the Alzheimer's caregiver. *Physical and Occupational Therapy in Geriatrics*, *3*(4), 133-38.

Winogrond, I.R., Fisk, A.A.. Kirsling, R.A., Keyes, B. (1987). The relationship of caregiver burden and morale to Alzheimer's disease patient function in a therapeutic setting. *The Gerontologist*, *26* (5), 336-339.

Wylie, C.M. (1970). The definition and measurement of health and disease. *Public Health Reports*, *February*, *85*, 100-104.

Zarit, J., Gatz, M., and Zarit, S. (1981). Family relationships and burden in long-term care. *Presented at the 34th annual meeting of the Gerontological Society of America*, Toronto.

Zarit, S.H., Orr, N.K., Zarit, J.M. (1985). *The hidden victims of Alzheimer's disease: Families under stress*. New York: New York University Press.

Zarit, S.H., Reever, K.E., and Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feeling of burden. *The Gerontologist*, *20*(6), 649-655.

Zarit, S.H., and Zarit, J.M. (1982). Families under stress: Interventions for caregivers of senile dementia patients. *Psychotherapy: Theory, Research and Practice*, *19*, 461-471.