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THE RELATIONSHIP OF CAREGIVER INVOLVEMENT AND SELECTED CAREGIVER SELF-CARE BEHAVIORS

By

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ABSTRACT

THE RELATIONSHIP OF CAREGIVER INVOLVEMENT AND SELECTED CAREGIVER SELF-CARE BEHAVIORS

By

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The purpose of this cross-sectional study was to determine if a relationship existed between caregiver involvement and the self-care behaviors of the caregiver. Involvement, which was the independent variable, was represented as ADL and IADL. Self-care behaviors, which were the dependent variables, were nutrition, exercise and sleep. Data utilized were collected among 233 primary caregivers through the use of interviews and self-administered questionnaires. Data were analyzed (secondary analysis) utilizing correlation. The significant findings were a negative pattern between involvement and self-care behaviors. Implications for future nursing research include the need to develop conceptually sound scales, the need to determine which variables have an effect on caregiver self-care behaviors, the need to determine which self-care behaviors are important to caregivers, the need to determine how caregiver self-care behaviors change over time and the need to conduct intervention studies to determine effective strategies to assist the caregiver.

To my loving wife Jill, whose patience strengthened my resolve to complete this project.

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CHAPTER I

The Problem

Introduction

The elderly are a growing segment of society. Weiler (1986) notes that in 1919 those people over 65 years of age comprised 4% of the population. In 1980 the same group was 11.4%, and in 2040 they will make up over 20% of the population. Fries and Crapo (1986) state that the elder members of society are subject to chronic debilitating diseases. Fries and Crapo indicate that chronic diseases begin early in life but symptoms may remain subclinical. The progressive nature of the chronic debilitating disease will manifest itself later in an individual's life. Families have traditionally cared for the debilitated family member (Palley and Oktay, 1983).

Patients with a chronic debilitating disease may experience a progressive loss of physical and/or cognitive function that renders them increasingly dependent on others to complete their daily care (Barnes, Raskind, Scott, & Murphy, 1981). It then falls principally on the family to step in and assume responsibility to insure that the individual receives basic care. Caring for a chronically debilitated family member can be stressful and may leave the caregiver little time to meet his or her own needs (Montgomery, Gonyea & Hooyman, 1985; Archbold, 1982b). Bohm and Rodin (1985) note that as a caregiver becomes involved in the care of the debilitated family member, the caregiver has less time to spend on his or her own needs, which may include self-care behaviors.

Research Question

The purpose of this paper is to explore the question of whether a relationship exists between the level of caregiving involvement and the self-care behaviors of the caregiver. Therefore, the research question asked is "what is the relationship between the level of caregiver involvement and the self-care behaviors of the caregiver?"

Self-care behaviors may be described as maintaining diet, controlling stress, exercising and resting (Pender, 1987). Involvement of the caregiver with the care of the debilitated family member is defined as assisting the family member with activities of daily living (ADL) and instrumental activities of daily living (IADL). (Given & Given, 1986). This study will assist health care professionals in developing programs and plans to promote high levels of health for the family caregivers.

Background

Palley and Oktay (1983) and Montgomery, et al. (1985) note that caring for family members has a long tradition. As the patient with a debilitating disease becomes more incapacitated, the family caregiver must invest more time in the patient's care. This leaves less time for the caregiver to maintain his or her own health. George and Gwyther (1984) found that caregivers of patients with a debilitating disease experience a decline in self-care behaviors.

Thornberry, Wilson and Golden (1986) conducted a study pertaining to self-care in which they attempted to compile baseline data concerning the degree to which a sample of noninstitutionalized people 18 years old and older engage in self-care behaviors. The sample consisted of 16,780 respondents. The noninstitutionalized population from which this sample was drawn consisted of 170,520,000 adults. From this sample of the noninstitutionalized population of the United States, the number of people engaging in the various self-care behaviors were estimated. The estimated population is based on a sample of noninstitutionalized adults rather than the population as a whole and may be subject to sampling error.

According to Thornberry, et al. (1986), in regards to diet, 55% of the respondents indicated they ate breakfast. Sixty four percent of all respondents stated they rarely or never discussed diet with a health care professional. Sixty one percent of the 45 to 64 year old group rarely discussed diet. Of all the respondents, 48% said their weight was about right while 41% of the 45 to 64 year olds and 52% of the 65 and older respondents stated their weight was about right. In regards to sleep, 66% of all respondents stated they had seven to eight hours of sleep per night. Sixty eight percent of the 45 to 64 year olds and 58% of the 65 and older group received seven to eight hours of sleep a night.

Thornberry, et al. (1986) further reported that 31% of respondents of all ages reported they experienced a moderate amount of stress in the previous two weeks. Thirty percent of the 45 to 64 year old respondents indicated they experienced a moderate amount of stress, but 46% of the 65 and older respondents indicated they experienced almost no stress in the previous two weeks. Fifty four percent of all respondents stated that stress hardly affected their health. Fifty five percent of the 45 to 64 year olds and 65% of the over 65 year old groups stated that stress hardly affected their health. This finding by Thornberry, et al. regarding stress may indicate that people in this study in general experience little stress, but it is not known if this would hold true if the population consisted of caregivers. Forty two percent of all respondents indicated that they exercised regularly, while 32% of the 45 to 64 year old respondents and 28% of the 65 and older respondents admitted to regular exercise.

Caring for the chronically debilitated person can produce stress in the family which can precipitate depression, sleeplessness and anxiety (Brody, 1985). Orem (1980) states that caregivers can perform self-care by assuming the primary responsibility for their care and accepting the nurse as collaborator to guide them in their pursuit of self-care.

There are many definitions for the key concepts in this study. In the following section, this researcher will provide definitions as used in this study.

Definitions of Concept

Several concepts related to the research question will be defined. The following definitions will serve as a reference point for the purpose of this study.

Self-care behaviors are "the practice of activities that individuals personally initiate and perform on their own behalf for the maintenance, restoration or promotion of health" (Joseph, 1980, p. 133).

Family caregiver is that person who provides primary day to day care to a debilitated elderly family member and is related to the patient either by bloodline or marriage (Given & Given, 1986).

Patient with debilitating disease is one diagnosed with at least one chronic illness by a physician and reported as in need of assistance with ADL and/or IADL (Given & Given, 1986).

Health is a state of psychological, social and biological well-being (World Health Organization cited in Pender, 1987).

Involvement are those daily caregiving activities provided by the caregiver for the benefit of the chronically ill dependent patient to provide for the patient's ADL and IADL. (Given & Given, 1986)

Activities of Daily Living (ADL) are basic self-care behaviors that need to be performed daily, which are eating, grooming, toileting, dressing, bathing, and ambulating. (Kane & Kane, 1981)

Instrumental Activities of Daily Living (IADL) are those activities related to living independently that need to be completed but not necessarily on a daily basis, which are housework, laundry, cooking, shopping, transportation, and handling the patient's money. (Kane & Kane, 1981)

Summary

The caregiver involved in caring for a chronically debilitated family member may be experiencing a decrease in the time spent on the caregiver's self-care behaviors. As the ill family member's status decreases, the caregiver's level of involvement increases. Orem's (1980) theory on self-care attempts to explain those factors involved in the origins of self-care and how nursing can assist in correcting a caregiver's self-care deficit.

In Chapter Two, Orem's (1980) theory of self-care will be discussed. In conjunction with this discussion of Orem's theory, a model will be introduced to explain how involvement and self-care are related. A discussion on how Orem's theory is related to nursing will complete the chapter.

CHAPTER II

Conceptual Framework

Overview

Orem (1980) has developed a theory of self-care that will be utilized as the basis for the conceptual model of this study. The areas which will be explored in this chapter include Orem's model, an explanation as to how the model was adapted for this study and how the conceptual model is related to nursing theory.

Orem's Model of Self-care

Orem (1980) defines self-care behaviors as "the practice of activities that individuals initiate and perform on their own behalf for the maintenance, restoration or promotion of health." (Orem, 1980, p. 35). Self-care is an ongoing process that helps determine the quality of life the individual will experience. Self-care behaviors can be enhanced through selective intervention by the nurse to increase an individual's knowledge and skills necessary to perform competent self-care behaviors (Pender, 1987). Orem places all self-care needs into an area she calls self-care requirements. Orem arranges self-care requirements into three groups. They are universal self-care requirements, developmental self-care requirements and health deviation self-care requirements.

Universal self-care requirements include:

1. Maintenance of sufficient air.
2. Maintenance of sufficient water.
3. Maintenance of sufficient food.
4. Provision of care associated with elimination processes and excrement.
5. Maintenance of a balance between activity and rest.
6. Maintenance of a balance between solitude and social interaction.
7. Prevention of hazards to human life, human function and human well-being.
8. Promotion of human functioning and development within social groups in accord with human potential (Orem, 1980, p. 42)

The eight universal self-care requirements are necessary in order for caregivers to meet their basic needs. If the caregiver cannot meet her or his own universal requirements because of involvement in the care of the debilitated family member, the caregiver may become ill.

Developmental self-care requirements include:

1. Maintenance of living conditions that support life processes, promote development or human progress toward higher levels of organization of human structure and maturation.
2. Provision of care either to prevent the occurrence of deleterious effects of conditions that can affect human development or to mitigate or overcome these effects from various conditions. (Orem, 1980, p. 47)

Developmental self-care requirements are those which help the caregiver meet her or his developmental needs, such as when the caregiver's lifestyle changes due to providing care for a debilitated person. If the caregiver cannot meet his or her own developmental requirements because of involvement in the care of a debilitated family member, the caregiver may become ill. Health deviation self-care requirements are not considered for the purpose of this paper because these assume the caregiver is ill or debilitated and not functioning independently to care for the debilitated family member.

According to Orem (1980), in order to determine if an individual can perform self-care behaviors, a number of factors must be considered. Self-care agency is "the ability of an individual to initiate and perform health activities for himself or herself in order to maintain life, health, and well-being." (Joseph, 1980, p. 133) Orem notes that this ability to perform self-care behaviors may be shaped by factors such as age, gender, health state and family system. By no means does Orem try to limit development of self-care agency to just these factors. Through the self-care agency a caregiver develops the ability to perform self-care behaviors throughout his or her life.

Orem (1980) defines self-care agent as the provider of self-care. A caregiver would therefore be her or his own self-care agent. Orem notes that specific self-care behaviors must be attended to for each individual and that the priority of these self-care behaviors vary from individual to individual. Therapeutic self-care demands are defined as "a specific set of actions needing to be performed by a self-care agent in order to accomplish beneficial self-care (requirements)." (Joseph, 1980, p.133) Each caregiver has her or his own therapeutic self-care demand and if these demands are not met, the caregiver will not be able to maintain her or his health. Therefore, if a caregiver has a therapeutic self-care demand for nutrition and is unable to attain it due to the caregiver's involvement with the debilitated family member, that therapeutic self-care demand will not be met. The same could be said for the self-care behaviors of sleep, exercise and stress management.

Orem (1980) notes that if the needs of the individual are not being met then a self-care deficit exists. Self-care deficit is defined "an inability to engage in self-care (behaviors), which occurs when the self-care agent is unable to meet the therapeutic self-care demand placed upon him or her owing to insufficient self-care agency." (Joseph, 1980, p. 133) The caregiver is therefore faced with a self-care deficit if she or he has an inadequate ability to perform self-care behaviors.

Orem's (1980) self-care model according to Joseph (1980), which was modified for this study, is diagrammed in Figure 1. The needs of the caregiver are described as universal or developmental self-care requirements. These include the self-care behaviors of nutrition, sleep, exercise and stress management. Therapeutic self-care demands are those self-care requirements that have priority over all other self-care requirements. The caregiver

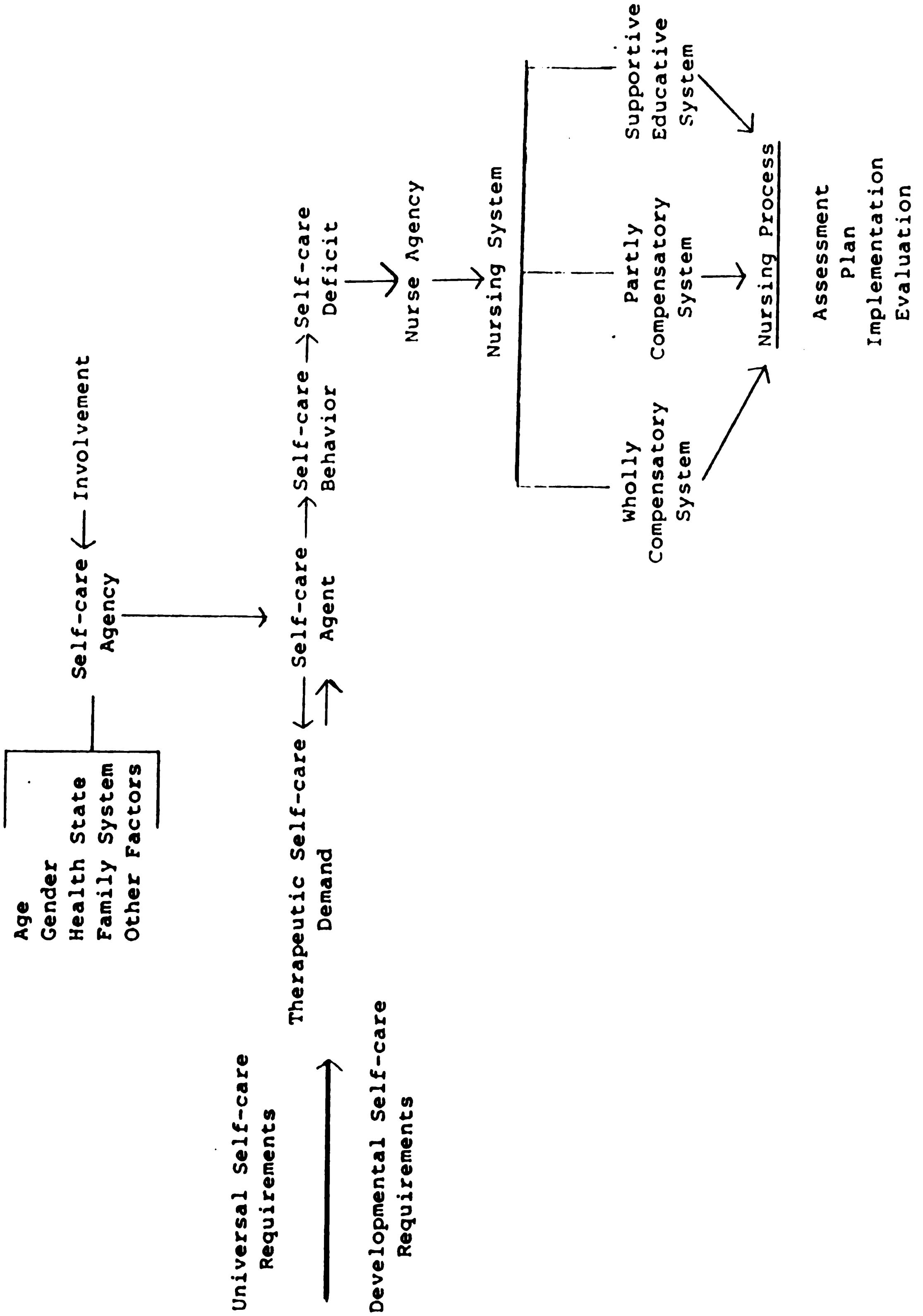

Figure 1

Modified Orem's Self-care Concept

(Joseph, 1980)

functions as his or her own self-care agent. The manner in which a caregiver reacts to his or her therapeutic self-care demand is determined by that individual's self-care agency.

As noted in Figure 1, self-care agency can be shaped or affected by a number of factors, including age, gender, health state, family system and other factors. These factors affect a caregiver's ability to react to a therapeutic self-care demand. Involvement enters Orem's model by affecting the self-care agency. According to this model, a caregiver's involvement with a debilitated family member will have an impact on the caregiver's self-care agency, or how the caregiver makes self-care decisions. When the caregiver acts on a therapeutic self-care demand, that caregiver is engaging in self-care behavior. Involvement affects how the caregiver makes decisions concerning self-care behaviors but does not directly affect the self-care behavior. If a caregiver is unable to meet a therapeutic self-care demand, a self-care deficit results. This self-care deficit can be due to the inability to perform self-care behaviors. The self-care deficit that cannot be met by the caregiver is then diagnosed by the Clinical Nurse Specialist who determines with the caregiver what level of care is needed to correct the caregiver's self-care deficit.

Orem has noted that there are three levels of nursing care: the Wholly Compensatory System, the Partly Compensatory System and the Educative/Supportive system. The

Wholly Compensatory System is one in which the nurse provides total care for the client. In the Partly Compensatory System the client is able to perform some care for himself or herself but still requires some physical care by the nurse. In the Educative/Supportive System the caregiver does not require physical care but rather guidance and emotional support.

Since the researcher in this study is interested in self-care at the primary care level, the nursing system used in the Orem model is the Educative/Supportive system. As a supporter and educator, the Clinical Nurse Specialist and the individual determine a plan of care by following the nursing process. The interaction of components of the model demonstrates how the Clinical Nurse Specialist adapts the model to each individual caregiver's needs.

Model For Study

A modified version of Orem's model involving the self-care agency and self-care behaviors will be used in this study. (See Figure 2). The self-care agency will focus only on involvement of a caregiver providing care to a dependent family member. Using this model, a theoretical relationship between caregiver involvement, self-care agency, self-care agent and self-care behaviors can be posited.

From the Orem model described, caregiver involvement is

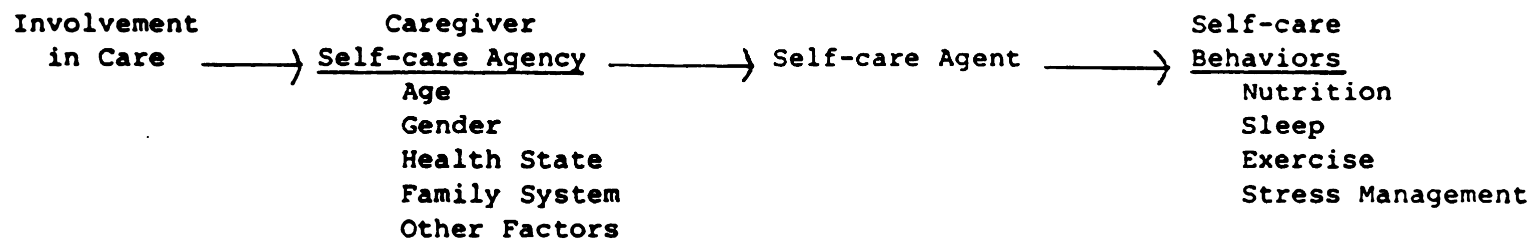

Figure 2

Proposed Study Model

the provision of care to the debilitated family member by the caregiver. Involvement has a direct impact on self-care agency. Self-care agency is defined as the ability of the caregiver to react to self-care demands (Joseph, 1980). That ability, according to Orem (1980) can be determined by a variety of factors such as age, caregiver gender, health state, family system, etc. Once the self-care agency is established, it can still be influenced by factors such as involvement in caregiving. Assisting a debilitated family member in the performance of ADL or IADL requires time, energy and knowledge. By becoming involved with a debilitated family member, the caregiver has less time and energy left over for herself or himself. The caregiver, as her or his own self-care agent, has many demands placed on her or him. The actual decision about which self-care behaviors to engage in is made by the caregiver.

As described previously, self-care behaviors are those behaviors needed to maintain health. According to the Orem (1980) model, how well these behaviors are performed can determine a caregiver's health. If the caregiver's self-care agency is consumed by involvement in the care of a debilitated family member, the self-care behaviors of the caregiver may also be affected. If involvement in caregiving increases sufficiently,the ability of the caregiver to perform self-care behaviors may be diminished. Therefore, according to this model it is hypothesized that as caregiver involvement increases, caregiver self-care behaviors performed decrease.

Relationship of the Problem to Nursing Theory

It is the responsibility of the nurse to help the individual to achieve all self-care needs. Orem (1980) states that nursing can be divided into three systems: wholly compensatory, partially compensatory and supportive-educative. It is the supportive-educative system that is utilized in this study. The supportive-educative system is described by Orem as a system in which an individual has the ability and inclination to develop and perform needed self-care requirements but is unable to do so without guidance. Approaches to achieve self-care requirements include teaching, providing support and constructing an environment conducive to growth and learning. When a client is fairly independent and capable of learning, the nurse can correct self-care deficits through the role of educator and consultant. The nurse educator can teach the client the skills and knowledge needed to promote health. As a consultant, the nurse can function as an advisor for the client so that the client can be selective as to which information he or she chooses to seek.

The Self-care Model, which is adapted from a portion of Orem's (1980) self-care theory, explains how involvement ultimately affects self-care behaviors. Involvement will have an impact on self-care behaviors by affecting the caregiver's ability to make health decisions through self-care agency. Furthermore, as the level of caregiver involvement increases, the caregiver has less freedom in determining how and when he or she will engage in self-care behaviors. For example, involvement affects self-care behaviors when a caregiver for a debilitated family attaches great importance to maintaining optimal health, but is unable to do so because the caregiver must expend much time caring for the family member. The caregiver then has little time for their own personal needs and is unable to meet the self-care demand for rest. Therefore, the caregiver is less likely to engage in self-care behavior.

Summary

In summary, Orem (1980) notes that an individual needs self-care to maintain her or his health. Without this ability to perform self-care behaviors the caregiver with unmet self-care needs can expect to experience a decline in his or her health. Self-care is a learned process and must meet essential needs such as food, water and rest. When needs are not met, a self-care deficit exists and the nurse assists in correcting the deficit. If the caregiver is not in a position in which a nurse can assist with correcting self-care deficits, the caregiver may not have any health care professional available to help him or her correct the self-care deficits. As the caregiver's ability to perform self-care is consumed by involvement in caring for the debilitated family member, the caregiver has less time and energy to engage in her or his own self-care behaviors.

In Chapter Three the literature will be examined to review pertinent research in the areas of caregivers, health promotion, self-care behaviors and involvement. A critique of the literature will assess the strengths and limitations of relevant studies.

CHAPTER III

Review of the Literature

Overview

The purpose of this study is to determine the relationship between the level of caregiver involvement and the self-care behaviors of the caregivers. However, before this can be done, a review of the literature that includes the areas of caregivers, health promotion, self-care behaviors and caregiver involvement must be completed. A review of the literature is conducted to determine what work has been completed, what still needs to be examined in the selected areas and how it relates to the purpose of the paper.

Caregivers

According to Montgomery, Gonyea and Hooyman (1985), families have the major responsibility of caring for the chronically ill elderly family mem+bers. Some families find caring for the elderly to be a burdensome experience. Archbold (1982 a and b) notes that caregivers tend to be spouses and adult children of the ill family member.

Archbold (1982b) uses the term "parentcaring" to describe the role reversal of the parent and child. As the parent becomes more frail, he or she gradually takes on the role of the child. The adult son or daughter assumes greater responsibility for the parent. Archbold (1982a) notes that the caregiver is usually middle age or older. Parentcaring places many demands on the caregiver in that she or he must meet the emotional and physical needs of the older individual while trying to meet her or his own needs. Therefore, the caregiver involved with the debilitated family member can become exhausted while trying to fulfill his or her caregiver responsibilities (Archbold, 1982 a and b).

Bohm and Rodin (1985) identify the family as a system. Therefore, how each member interacts with the other members affects the system or family as a whole. A family member who is debilitated affects the family by his or her dependency. The family is also affected by the caregiver, trying to meet his or her own needs while meeting the needs of the patient. The caregiver may experience difficulty meeting the needs of the patient and her or his own needs. George and Gwyther (1984) note that caregivers with a family member having a debilitating condition living at home experience a decline in self-care behaviors, a decline in the time spent on social-recreational activities and dissatisfaction with the quality of their life.

Baines (1984) conducted a descriptive study to gather baseline data pertaining to caregiver stress. The average age of the 50 caregivers studied was 73 years old and 78% of the caregivers were female. Seventy two percent of the caregivers were spouses and 67% of the caregivers had children. The average age of the patient was 79 years. Baines found that caregivers need to be given a break from caregiving duties to allow time to engage in self-care behaviors. Baines concluded that because of the caregiver's involvement with the patient, he or she does not have the time to engage in self-care behaviors.

Archbold (1982a and b) found that most caregivers enter the arrangement without fully understanding the commitment they are making towards providing 24 hour care. Caring for a patient who is physically and mentally impaired is more demanding than caring for children. In caring for children, the level of dependency on the caregiver decreases with time or as the child matures into adulthood. In the case of the debilitated adult patient, the dependence and level of care may increase with time if the patient's condition deteriorates. This arrangement of providing care for a debilitated member of the family may continue for many years. The stress of providing care may stem from several causes, such as social isolation, lack of privacy, suffering from providing heavy labor, financial drain or the interruption of a career. Physical illness may be manifested as a result of the prolonged stress. According to Archbold (1982a), the more common health problems that may be seen are depression, obesity and hypertension.

Archbold (1980) found that caregivers tend to neglect their own health care in order to care for their debilitated family member. Three of six caregiving families in the study conducted by Archbold experienced a substantial health problem after they began caring for the debilitated family member. The health problems of these families were not caused by the caregiving situation, but these families felt that the caregiving situation exacerbated their health problems. Three caregivers expressed feelings of anger and depression over their caregiving situation. All caregivers found the caregiving situation increased stress within the family. From this study it is noted that exacerbation of existing health problems may be related to caregiving.

Stone, Cafferata and Sangl (1987) examined data gathered from a survey conducted by the Bureau of the Census for the Department of Health and Human Services. The instrument used was the Informal Caregivers Survey. This instrument gathered a variety of information about caregivers including age, race, living arrangements, marital status, health status and employment status. The main criterion for inclusion in the study was that the family member needing care required assistance with at least one activity of daily living or one instrumental activity of daily living. The researchers randomly selected 36,000 individuals from the Medicare records. These individuals were screened and interviewed by telephone and 1,924 agreed to participate in the study.

The purpose of the study by Stone, et al. (1987) was to establish a profile of caregivers. The major findings of the study were seventy two percent of the caregivers were female and the average age of the caregivers was 57 years old. Seventy five percent of the caregivers lived with the debilitated family member, thirty one percent of the caregivers were employed and fifty one percent of the caregivers were married to the debilitated family member.

Killeen (1989) studied 120 caregivers. The average age of the caregiver was 57 years old. Of the sample, 79% were female. Thirty eight percent of the caregivers were spouses of the debilitated family member. Killeen's study supports past studies by Archbold (1982a and b), Baines (1984) and Stone, et al. (1987) in that caregivers tend to be older women who are either daughters or wives of the debilitated family member.

In summary, according to the literature, caregivers tend to be spouses and adult children. The literature also indicates that caregivers tend to be females who are wives or adult daughters of the patient (Archbold, 1982 a & b) and that caregivers are middle-aged (Stone, et al., 1987; Killeen, 1989).

Health Promotion

Literature pertaining to health promotion and how it is related to caregiving will be reviewed in this section. It should be noted that in the literature the terms "health promotion" and "self-care" are quite often used interchangeably.

Mullen (1986) describes health promotion as a combination of disease prevention and attempts to maintain wellness. Disease prevention takes place through: 1) risk reduction for those individuals judged to have risk of a disease and 2) preventing development of risk factors for those persons not at risk for developing disease. Wellness is seen as those attitudes and behaviors that increase an individual's quality of life. Individuals who have a high level of wellness tend to be motivated by a need to experience life and not just avoid disease. Mullen is inferring that a relationship exists between wellness and health promotion.

Laffrey (1985) notes that there are four dimensions of health promotion: clinical health promotion, role performance, adaptive health promotion and eudaimonistic health promotion. Clinical health promotion is the facilitation of the absence of disease. An example of this dimension of health promotion is that occasion when the caregiver seeks the health care professional for guidance. The caregiver is confronted with a health problem that exceeds the caregiver's self-care abilities. Role performance health promotion is promoting an individual's capability to perform his or her role as expected by society. In this case, the nurse assesses the patient's current roles (husband/wife, father/mother, employee, etc.), how well he or she is fulfilling those roles and how new roles (such as caregiver) can be integrated. Adaptive health promotion is the ability of an individual to interact with others and the environment. The nurse may assist the client in adapting to stressful situations by indicating community resources available. Laffrey (1985) defines eudaimonistic health promotion as the promotion of an individual to achieve her or his highest potential.

Somers and Weisfeld (1983) note that since 1982 the United States government has enacted changes in laws pertaining to Medicare and the retirement age. Somers and Weisfeld state that prior to this time it was generally believed that disease prevention and health promotion for the over 65 year old population was a waste of time since after years of inactivity, poor diet habits and smoking, the health of the elderly person was irreparably damaged. Somers and Weisfeld note that while damage from neglect or lack of health promotion activity is many times irreversible, the elderly may benefit from health promotion activity to halt the eroding of their health and may help prevent the occurrence of any new disorder. When dealing with the elderly, "health" refers to the degree to which an individual is able to function independently, even in the presence of a disability. The goal of health care "should be promotion of the maximum functional independence which the individual is capable of maintaining." (Somers & Weisfeld, 1983, p. 11).

Atchley (1981) notes that elderly members of our society are capable of taking an active role in their health care. Health promotion is based on the idea that people choose to engage in healthy behavior; the elderly can be viewed as a group that can partake in health promotion.

In their review of the literature, Kane, Kane and Arnold (1986) found that it is difficult to show direct effect of preventive action on health status with older individuals because there are many factors influencing their health. Kane, et al. are implying that there are many factors that could have an adverse influence on the health of the elderly. Therefore it may be difficult to demonstrate cause and effect of self-care behaviors and the caregiver's health.

In a study involving 6900 participants with a range in age of 20 years to 80 years and an average age of 42, Belloc and Breslow (1972) found a positive relationship between health promotion and overall health. This relationship held true even when the variables of age, sex and economic status were considered. This implies that healthy people are engaged in health promotion.

Fries and Crapo (1986) state that at the turn of the century the primary cause of death was infectious diseases. With the advent of drugs and other discoveries in health care, the infectious disease death rate has decreased by approximately 85% to 99%. The primary causes of death among adults are chronic diseases, notably heart disease and cancer (Fries & Crapo, 1986). Fries and Crapo indicate that chronic diseases have several similarities: 1) they are progressively debilitating, 2) they affect different people similarly, and 3) there is a threshold where clinical symptoms are observed. As a chronically ill individual's disease progresses, he or she may require increasing assistance from a caregiver.

Chronic diseases begin early in life but may not become symptomatic until later in life. The diseases will progress until the person can no longer compensate for the loss of function when death occurs. As Fries and Crapo (1986) note, chronic diseases cannot be halted but their progression can be slowed, which will delay the appearance of clinical symptoms. To slow or delay the chronic disease's progression the individual must avoid actions or risk factors that can increase the progression rate of the disease. Identified risk factors include smoking, obesity, inactivity or sedentary lifestyle, poor diet habits and living under constant stress. If the caregiver is experiencing a chronic illness, the self-care behaviors utilized may delay the progression of the chronic illness.

Weiler (1986) states that the over 65 year old age group is a growing segment of society. If they are to remain productive, health promotion is needed. If caregivers are elderly, they must utilize health promotion in order to continue as caregivers.

Ory (1984) states that most of the noninstitutionalized elderly have a minimum of one chronic health condition. In this population, health promotion should consist of reducing dependency caused by chronic conditions and preventing any further dependency by increasing their social network and knowledge of health practices. Nurses should focus on assisting the elderly understand their health situation by using a variety of educational approaches. Cameron (1986) notes that the elderly will engage in self-care behaviors if provided with information and instructed in proper technique. Benson and McDevitt (1986) indicate that the elderly prefer to remain independent and can do so if they maintain their health. Nurses are in a position to educate the elderly in self-care behaviors so that the elderly can maintain their health and independence.

Arnold, Kane and Kane (1986) report that in health promotion the elderly are not specifically studied. Results from studies using younger people are generalized to the elderly. Until recently (Killeen, 1989), there were very few studies utilizing elderly subjects to demonstrate what factors may influence self-care behaviors.

Killeen (1989) studied 120 caregivers with an age range of 27 to 93 years and a mean age of 57. Seventy nine percent of the caregivers were female, 48% were daughters and 22% were wives of the debilitated family member. The criteria for inclusion in the study were the individual had to be the primary caregiver for a patient over the age of 65 and the care had to be provided at home. Instruments used were the Personal Lifestyle Questionnaire and the Current Health Scale. The Personal Lifestyle Questionnaire measures health promotion and had a reliability of .83. The Current Health Scales measures caregivers' health perceptions and had a reliability of .92. The researcher correlated the scores of the two instruments and found a positive relationship between utilization of health promotion behaviors such as nutrition, relaxation and exercise, and a caregiver's perceived health status. This indicates that participation in health promotion behaviors was related to the caregiver's positive perception of his or her health state. (Killeen, 1989).

To summarize, health promotion is the behavior the individual exhibits when engaging in activities that may foster optimal health. From the literature examined, it has been noted that there is a positive relationship between engaging in health promotion activities and perception of better health (Killeen, 1989). This is important to note because it is the perception of better health that could encourage a caregiver to engage in self-care behaviors/health promotion activities. Researchers are beginning to examine health promotion as it relates to more elder populations (Cameron, 1986; Killeen, 1989).

Self-care Behaviors

Breslow and Somers (1977) developed a program to identify health care goals and services related to different age groups. The authors suggest that if individuals engage in self-care behaviors throughout their lives, they may live a healthier existence. (Breslow & Somers, 1977).

Orem (1980) has noted a number of self-care requirements as previously discussed in Chapter Two. The self-care behaviors of nutrition, exercise, sleep/rest and stress management comprise the core of Orem's self-care requirements.

Milsum (1980) states that lifestyle can be a major contributor to illness. That is, if the lifestyle is not meeting an individual's needs, he or she runs the risk of developing an illness. Milsum describes three determinants of health:

1. Nutrition: food, drink, air and water. Also included are pollutants such as smoke.
2. Physical fitness: exercise and physical work.
3. Stress management: methods used to cope with stress such as exercise, aloneness, relaxation and prayer.

In addition to the three components of health Milsum (1980) has identified, the National Institute on Aging (1981) has identified sleep/rest as a fourth component of health. Bausell (1986) identified a number of self-care behaviors. Among these self-care behaviors were nutrition, sleep, exercise and stress management.

A review of the literature regarding nutrition, stress management, exercise and sleep/rest will be conducted in order to demonstrate what research has been performed in these areas.

Nutrition

Pritkin and Cisney (1086) indicate that part of the aging process includes a decrease in the ability to absorb nutrients from the gastrointestinal tract. Degeneration of the teeth, gums and tongue also occurs which makes chewing food difficult and tasteless. Pritkin and Cisney state that the elderly need balanced diets in order to maintain their health. Diets of older people have been linked to cancer, diabetes, cardiovascular disease, osteoporosis, anemia, renal disease and gout. Finally, nutrition may be a problem with the elderly due to their lack of knowledge or resources to maintain a healthy diet.

Freedman and Ahronheim (1985) indicate that there is no evidence that the dietary needs of the elderly differ from other age groups. The elderly therefore need to eat balanced diets to maintain healthy bodies and prevent excessive weight changes. Therefore, if the caregivers are going to maintain or promote their health, they must be able to perform the self-care behavior of providing adequate nutrition for themselves.

Cooper and Gardner (1989) indicate that one means of determining the relative nutritional status of the elderly is by examining serum albumin levels. Cooper and Gardner argued that if an individual was nutritionally deficient, the serum albumin level of the individual would be low. The sample consisted of 241 noninstitutionalized volunteers who were recruited at health fairs and a Veterans Administration ambulatory clinic. Ages ranged from 55 to 101 years of age. Blood samples were drawn and serum albumin levels were measured utilizing laboratories certified by the Centers for Disease Control. Data analysis used linear regression.

Cooper and Gardner (1989) found that there was an approximately 4% per decade decrease in serum albumin levels for those individuals over the age of 70. Individuals under the age of 70 showed no relationship between serum albumin level and age. Cooper and Gardner concluded that the small decline in serum albumin levels was due to aging. Larger decreases in serum albumin levels could indicate a nutritionally deficient status.

Stress Management

Hooyman and Lustbader (1986) note that caring for a disabled family member is stressful. Hooyman and Lustbader state that stress is derived from three sources: physical, financial and emotional factors. Physical stress is derived from the actual work or caregiving, such as lifting, washing and meal preparation. Financial stress results from the added costs of caring for the family member and possible loss of employment. Emotional stress may be due to the constant care the family member requires or the loss of personal freedom and friends. Continued stress on the caregiver may lead to a decline in his or her health because he or she cannot control all stressors. Therefore, the caregiver must find outlets for relieving stress (Hooyman & Lustbader, 1986).

Baines (1984) conducted a descriptive study of 50 family caregivers. The sample was nonrandom. Criteria for inclusion in the study were both caregiver and debilitated family member were at least 65 years of age and care had to have been provided in the home for at least one month. Caregiver mean age was 73 years and patient mean age was 75 years. Seventy two percent of caregivers were spouses of the patient. The instrument used was the Chronicity Impact and Coping Instrument, which examined methods of coping with caregiving and concerns of the caregiver. Baines does not report reliability for this instrument.

Baines (1984) found that the greatest stressor for the caregiver was providing continuous care for the debilitated family member. Relief of this stress may be brought about by providing intermittent relief for the caregiver so that she or he may have a break in routine and be able to take time for herself or himself. Teaching the caregiver to recognize and deal with her or his stress helps the caregiver to better cope with stress (Baines, 1984).

Stone, Cafferata and Sangl (1987) identified role conflict as a source of stress. Caregiver role conflict is defined as the clashing of expectations for behavior between the patient and the caregiver and other family members. According to Stone, et al., role conflict is experienced more often among wives who are the caregivers.

Brody (1985) notes that parent care provided by family members produces stress within that family. Many of the symptoms of stress take the form of "depression, anxiety, helplessness and sleeplessness." (Brody, 1985, p. 22). These symptoms can be precipitated by changes in the family's life style and recreational activities, by loss of freedom, isolation from friends and other support systems and the demands of increased responsibilities. Therefore, as the caregiver situation intensifies and the caregiver becomes more stressed, the caregiver may have less time to take care of his or her own needs. Reestablishing support systems and recreational activities are some means to reducing or managing the caregiver's stress.

Given, Collins and Given (1988) reported that caregiving can be both physically and emotionally stressful for the caregiver. The caregiver may experience feelings of "isolation, sadness and frustration" (Given, Collins & Given, 1988, p. 78).

Cantor (1983) found that the stress experienced by family caregivers is experienced differently according to the relationship of the patient and the caregiver (patient-spouse, patient-adult child or patient-relative: niece, nephew, brother, etc.).

Exercise

Abbot (1986) found that 50% or more of the population over 65 years of age has some chronic condition that can interfere with their level of physical activity. Abbot states that people in this age group that exercise regularly have greater amounts of energy, less anxiety, get more complete sleep and experience more life satisfaction.

According to the National Association For Human Development (1976), when people do not exercise their tissue gradually loses its ability to cope with activity. Exercise therefore helps maintain tissue function. As people age they will experience some loss of function through degeneration. Exercise may help the older individual slow down this degenerative process and maintain his or her level of activity.

Bortz (1982) has hypothesized that many of the changes associated with aging, such as decreased cardiac output and loss of muscle mass, may be due to inactivity. Thomas and Rutledge (1986) note that regular exercise in the elderly helps maintain or improve muscle/bone strength, loss or gain of weight and emotional health. Inactivity may lead to a decline in a caregiver's health. Engaging in the self-care behavior of exercise may help the caregiver promote his or her own health.

Morey, Cowper, Feussner, DiPasquale, Crowley, Kitzman and Sullivan (1989) studied the effects of exercise on a group of elderly subjects. The study consisted of 49 subjects over the age of 64 selected from a population of patients at a Veterans Administration outpatient clinic. The subjects were randomly selected regardless of health status with the only exception being amputees, nursing home residents and those not able to function in a group.

The mean age of the subjects in the study by Morey, et al. (1989) was 70 years. Ninety four percent of the subjects were male and 84% were Caucasian. The subjects averaged 1.6 chronic diseases including arthritis, hypertension and heart disease. Pre-exercise assessments were performed on the subjects to verify their health status. For 17 weeks, subjects attended a supervised exercise program three days a week. The investigators performed follow-up health assessments on the subjects. Data were analyzed using paired t-tests.

Morey, et al. (1989) found that the results of the post-exercise examination indicated a decrease in the resting heart rate, an increase in abdominal strength, an increase in muscle flexibility, as measured by hamstring length, and a decrease in body weight, fat and cholesterol. Morey, et al. concluded that supervised programs for the elderly are beneficial.

Sleep/Rest

Dement, Miles and Carskadon (1982) note that changes occur with an individual's sleep/wake pattern as they age. This may be due to changes in an individual's routine such as occurs with retirement. Another possible cause for changes in an older individual's sleep/wake cycle may be decreased exercise. Dement, et al. also state that disturbances in sleep can lead to daytime drowsiness. Dement, et al. indicate that the elderly try to compensate for their sleep disturbances by taking daytime naps or using hypnotics. The use of hypnotics can decrease an individual's response time. The caregiver may have difficulty performing the skills needed to care for the debilitated family member. Continued disturbance in sleep patterns can lead to depression.

According to the National Institute on Aging (NIA) (1981), sleep disturbances in the aged may be due to sleep apnea, nocturnal leg twitches and changes in circadian rhythm. Sleep disturbances may also be due to depression, stress or the use of alcohol or drugs. Sleep disturbances can lead to daytime napping followed by nighttime insomnia. Therefore, the self-care behavior of sleep/rest is needed in order to prevent a possible decline in the caregiver's health.

Davis (1986) states that older people can experience sleep disturbances in the form of "difficulty falling asleep, frequent awakenings or restless sleep" (Davis, 1986, pp. 136-137). Davis notes that changes in lifestyle can have an important impact on the elderly person's sleep pattern.

Johnson (1985) conducted a correlation study of a nonrandom sample of 75 subjects. Ages ranged from 65 to 98 years with a mean age of 83 years. Fifty seven of the subjects were female. One third of the subjects took acetaminophen nightly, one third took a benzodiazepine nightly and one third took no nightly medication. Patients with Alzheimer's disease, Parkinson's disease, alcoholism, depression or those who took medications known to disrupt sleep patterns were excluded from the study. The instruments used by the investigator were a demographic data sheet and the Sleep Pattern and Daytime Behavior Questionnaire.

Results of the study by Johnson (1985) demonstrated that regardless of whether or not the patients took nightly medications, they perceived some disruption in sleep patterns. Females had more complaints of sleep disruption than males. Johnson found no relationship between age and perception of sleep disruption. Those patients taking no nightly medication reported the least amount of complaints about their sleep patterns and those taking benzodiazepines reported the most complaints. Johnson concluded that the elderly experience changes in sleep patterns and non-pharmaceutical approaches to sleep are the preferable means of treatment.

In summary, caregivers must be able to provide adequate nutrition for themselves in order to maintain their health (Pritkin & Cisney, 1986; Freedman & Ahronheim, 1985). Being nutrtionally deficient is not a normal state for the elderly (Cooper & Gardner, 1989). Caring for a debilitated family member may cause physical, financial and emotional stress for the caregiver (Hooyman & Lustbader, 1986). Exercise may help the caregiver maintain his or her energy level and strength (Abbot, 1986). Exercise by the elderly may help to maintain health by slowing down the degenerative process associated with aging (National Association for Human Development, 1976). Supervised exercise programs can be beneficial for the elderly (Morey, et al., 1989). Continued disturbance of sleep patterns which may be encountered when caring for a debilitated family member may adversely affect the caregiver (Dement, Miles & Carskadon, 1982; National Institute on Aging, 1976; Bortz, 1982). The elderly report changes in their sleep patterns and experience the least amount of sleep disturbances when a non-pharmaceutical approach is utilized (Johnson, 1985). Further study is required to better understand how disruption of self-care behaviors may be related to the caregiver's involvement with a debilitated family member.

Caregiver Involvement

According to a study commissioned by the House Subcommittee on Human Services (1987), caregivers who do not institutionalize the patient take on the responsibility to provide all facets of care for the patient. The degree of involvement varies among families and is dependent on the extent of debilitation the patient experiences. Instrumental activities of daily living (IADL) the patient's family may perform include shopping, housekeeping, meal preparation and transportation. Shopping includes going to a store to purchase items for the debilitated family member. Housekeeping encompasses sweeping, washing dishes and other routine maintenance activities to keep a household in working order. Meal preparation may include planning and cooking the meal. Transportation may involve providing transportation or arranging for transportation for the debilitated family member.

Kane and Kane (1981) identify activities of daily living (ADL) as behaviors performed by the patient's family and include bathing, dressing, toileting and feeding the patient. Each of these ADL are basic functions that every individual needs to perform to maintain her or his health. If an individual is unable to do so for herself or himself, then a caregiver could step in and assist the debilitated family member perform this function (Kane & Kane, 1981).

According to the House Subcommittee on Human Services (1987), caregiver involvement ranges over a spectrum depending on the level of disability of the family member. At one end of the spectrum, caregivers provide assistance with IADL functions for the family member who is still able to provide some care for himself or herself. At the other end of the spectrum, caregivers provide assistance with ADL functions for the family member who has little or no ability to complete ADL. Therefore, the caregiver may start out running errands or taking the family member to the store, but as the level of disability increases for the family member the caregiver may be bathing, dressing or performing other forms of personal care for the family member who is not able to perform these for himself or herself. According to the study by the House Subcommittee on Human Services, 85% of caregivers assist the elderly with transportation or shopping and 66% of caregivers assist with eating, bathing and dressing the patient. The study was inconclusive as to whether or not the involvement in care causes a decline in the health of the caregiver.

Kane and Kane (1981) state that ADL are those activities that deal with self-care. Many assessment tools for ADL measure the degree of independence that an individual has when performing ADL. This degree of independence can range from fully independent to fully dependent on a caregiver (Kane & Kane, 1981). ADL functions such as bathing, toileting, dressing and feeding are behaviors that must be performed in order for an individual to meet daily needs. If an individual is unable to perform ADL for herself or himself, then a caregiver may become involved in the individual's care in order to allow for that debilitated person to be able to complete ADL functions. Examples of ADL measurement tools are Older Americans Resources and Services (OARS) (Duke University Center for the Study of Aging and Human Development, 1978) and FAI (Functional Assessment Inventory) (Pfeiffer, Johnson & Chiofolo, 1981).

Kane and Kane (1981) and Fillenbaum (1985) both note that measuring IADL is more difficult than measuring ADL because IADL tasks may not be normally engaged in by the individual. For example, if an elderly man has never done the laundry and has always relied on his wife to perform this task, how would he answer the question of does he need help with laundry? As previously discussed, ADL and IADL are functions that must be completed in order for a debilitated family member to maintain a lifestyle. A method to determine how involved a caregiver is with the debilitated family member is to measure how frequently the caregiver assists with ADL and IADL. Assisting the debilitated family member with ADL and IADL is measurable and can establish the level of involvement the caregiver has with the debilitated family member.

At present ADL and IADL tools are being utilized to act as predictors for future performance by the elderly (Kane &

Kane, 1981). Kane and Kane note that the choice of assessment tool for ADL and IADL can affect results. Kane and Kane; Pfeiffer, Johnson and Chiofolo (1981) and Fillenbaum (1985) all indicate that tools for assessing ADL and IADL need more refinement in order to become more reliable and valid.

Horowitz (1982) conducted a secondary analysis on a larger study (The Role of Families in Providing Long-term Care to the Frail Elderly Living in the Community). The nonrandom sample consisted of 131 subjects. Seventy six percent were female. Caregiver age ranged from 26 to 69 years with a mean age of 51 years. Subjects were identified as the primary caregiver for an older person. The patient was receiving home or day care services. The involvement instrument, a modified OARS, measured ADL and IADL items such as transportation, cooking, personal care and financial management, and had a reliability of .82. Using correlation, it was found that caregiver involvement had an effect on caregiver health. Thirty three percent of the study's respondents reported a decline in health status that ranged from fatigue to peptic ulcer. The decline in health was attributed to the stress of caring for the patient. Horowitz notes that the degree of involvement affects the strain the caregiver experiences that may affect her or his health.

Bader (1985) found that providing around the clock care for a debilitated patient may be detrimental to the caregiver's physical and mental health. The caregiver who is heavily involved in the debilitated family member's care has little time for her or his own needs. Bader recommends the use of respite care to allow the caregiver time to meet her or his own needs.

In summary, caregivers may be involved with assisting a debilitated family member in performing ADL and IADL (House Subcommittee on Human Services, 1987; Kane & Kane, 1981). ADL and IADL are viewed in the literature as two different sets of skills (Kane & Kane, 1981). Several tools are available for measuring ADL and IADL, but all of them need some refinement to increase their reliability and validity (Cairl, et al., 1983; Fillenbaum, 1985).

Critique of the Literature

After reviewing the literature, strengths and limitations were noted. Each section discussed in this chapter will be critiqued.

Caregivers

A number of studies (Baines, 1984; Stone, et al., 1987; Killeen, 1989) have described characteristics of caregivers. Some investigators (Stone, et al., 1987) have used random sampling in their studies. Demographic instruments are used in a number of studies (Stone, et al., 1987; Killeen, 1989).

These instruments were used to collect data pertaining to caregivers and included gender, age, race, marital status, employment status and financial status. Investigators use descriptive statistics in their studies (Stone, et al., 1987; Killeen, 1989). Findings of more recent studies seem to support past studies (Killeen, 1989; Baines, 1984; Archbold, 1982 a & b). In general, researchers have found that the typical caregiver is a Caucasian woman in her middle to older years who is caring for her husband or parent.

Deficiencies in the caregiver literature can be noted. Subjects were usually accrued by referral from community agencies or recruited through health fairs. Although samples were reported to be random, investigators were limited to those subjects who agreed to participate. Since study subjects were volunteers, it is difficult to generalize the study results to the caregiver population as a whole. Interviewing techniques employed by researchers tended to eliminate some potential study subjects because of the caregiver's socio-economic status. Stone, et al. (1987) used the telephone to interview caregivers. This automatically excluded those caregivers unable to afford a telephone. Baines (1984) and Killeen (1989) are representative of researchers who do not provide examples of the instruments utilized in their studies. While researchers inform the reader of the instruments used and where the instrument can be located, researchers tended not to provide examples of the instruments. Researchers also tended to provide minimum data on scales derived from the instruments used, such as reliability. A reader is left with little information to judge for themselves the strength of an instrument used in a study. Also, researchers do not seem to include representative samples from various racial/cultural groups or economic strata.

In summary, attempts have been made to identify caregivers, but because of methods used by investigators, only a portion of the caregiver population is being investigated. More studies need to be conducted that include representative samples from various racial/cultural groups. Also, studies need to be conducted to examine caregivers at the different economic strata. The researcher may have to use face to face interviews instead of telephone or mailed questionnaires in order to reach a broader cross section of the caregiver population. In this way, it would be hoped that a more realistic composite of the caregiver profile could be established.

Health Promotion

Researchers are beginning to use the elderly in studies to determine health promotion activities (Cameron, 1986; Killeen, 1989). Researchers, such as Belloc and Breslow (1972) and Killeen (1989), utilize correlation analysis, which is appropriate for the data collected. The instruments utilized allow caregivers to indicate their level of health. Killeen (1989) for example, examined six areas of health promotion that included nutrition, exercise, relaxation, safety, substance use or avoidance, and general health. Therefore, it is possible to get an idea of a caregiver's health.

A number of deficiencies in the health promotion literature can be noted. Researchers, such as Killeen (1989), used nonrandom samples of subjects who were recruited through community agencies. This makes generalizing results from the study to the caregiver population as a whole, difficult. Examples of instruments utilized by researchers were not included in articles (Killeen, 1989; Belloc & Breslow, 1972), but reliability was reported. This makes it difficult for the reader to judge the appropriateness of the instruments. Areas of health promotion that seem to be lacking in the literature are mental health promotion, how physical health affects mental health and how chronic illness affects health promotion. Another area that seems to be lacking in health promotion studies are longitudinal studies that track health promotion activities over time.

To summarize, researchers are beginning to utilize elder subjects in studies and are using appropriate data analysis. Nonrandom samples have been used in some studies. Instruments utilized in studies are not included in articles. Researchers need to continue studies that utilize elder subjects in longitudinal studies. Studies need to focus on how the elderly promote their mental health, physical health and deal with their own chronic illnesses.

Self-care Behaviors

Some researchers investigating self-care behaviors have used elderly subjects in their studies (Cooper & Gardner, 1989; Baines, 1984; Morey, et al., 1989; Johnson, 1985). Cooper and Gardner and Morey, et al. collected data by objective means and did not rely on subjects' reports. This indicates that results from these studies are more likely to be reliable.

Several deficiencies can be noted in the self-care behavior literature. Nonrandom samples have been used (Baines, 1984; Cooper & Gardner, 1989). Therefore, it is difficult to generalize results to the caregiver population as a whole. While studies have included elder subjects, the instruments utilized were not tailored specifically for elder subjects. No data were presented to convince the reader that scales developed from instruments used in studies were psychometrically sound. Some researchers (Baines, 1984; Johnson, 1985) who utilized instruments did not report reliability for the instruments. These same researchers also failed to include examples of the instruments used in the studies. Killeen (1989) included the dimensions of nutrition, exercise, relaxation, safety and use or avoidance of alcohol and tobacco. Cooper and Gardner (1989) included the dimension of nutrition. Johnson (1985) examined the self-care dimension of sleep. Morey, et al. (1989) examined exercise in the elderly, and Baines (1984) studied stress. Examples of areas of self-care behavior that need to be studied in the elderly include substance abuse, self-examinations for breast, testicular and bowel cancer, eye care and sexual behavior.

In summary, some researchers investigating self-care behaviors have used elderly subjects. Some researchers have used objective means to collect data. Deficiencies in the literature include the use of nonrandom samples, the lack of reliability figures and psychometrically sound scales and examples of instruments researchers have used. While researchers are beginning to investigate some dimensions of self-care, more work needs to be done on previously examined self-care behaviors. Researchers must also endeavor to investigate previously unexamined areas of self-care behaviors.

Caregiver Involvement

A review of the literature pertaining to caregiver involvement demonstrates that studies have been conducted investigating caregiver involvement (House Subcommittee on Human Services, 1987; Horowitz, 1982). Horowitz demonstrates that ADL and IADL are measurable and can be measured reliably. However, while ADL and IADL can be measured, studies examined demonstrate how an individual performs the functions of ADL and IADL for themselves. No studies have been noted that measure involvement by how frequently a caregiver assists the patient with ADL and IADL. Therefore, more research is needed to investigate how a caregiver is involved with the debilitated family member.

To summarize, researchers have investigated caregiver involvement and have demonstrated that ADL and IADL can be measured. Past research has examined caregivers performing their own ADL and IADL. Future research must center on caregivers who perform ADL and IADL for the debilitated family member.

Review of the Literature Summary

A review of the literature was conducted in the areas of caregivers, health promotion, self-care behaviors and caregiver involvement. After reviewing the literature, several strengths and limitations were noted.

Killeen (1989) indicates that there is a positive relationship between caregivers who engage in health promotion activities and the caregivers' perceptions of better health. More recent studies have utilized elderly subjects (Cameron, 1986; Killeen, 1989). However, studies have not examined elderly subjects as a group in how elders engage in health promotion activities. More study is needed to specifically examine the elderly.

Studies have been conducted pertaining to the self-care behaviors of nutrition, stress management, exercise and sleep/rest. These self-care behaviors can benefit those individuals who are typically caregivers (Morey, et al., 1989; Johnson, 1985). However, studies on self-care behaviors as related to the elderly are limited in number. Also, the self-care behavior studies available for review examine only a limited number of self-care behaviors. More study is needed to examine self-care behaviors of the elderly. Investigators have demonstrated how caregiver involvement can be measured (House Subcommittee on Human Services, 1987; Kane & Kane, 1981). However, no study available for review examined caregiver involvement in how frequently the caregiver performed ADL and IADL for the debilitated family member. More study is needed to examine caregiver involvement as it is defined for this study.

Studies reviewed indicate that instruments for measuring concepts such as self-care behaviors are under development. No study reviewed supplied data to demonstrate psychometric soundness or appropriate instruments. Further study is needed to develop instruments that are psychometrically sound. A number of investigators have failed to give examples of the instruments utilized in their studies (Killeen, 1989). Some investigators also fail to report reliability and other properties for the instruments utilized (Baines, 1984; Johnson, 1985). An important deficiency in the literature is the limited reference of how nursing is able to assist the caregiver of the patient with a debilitating condition.

Following the literature review, one could conclude that a study needs to be conducted that utilizes elderly subjects while investigating how their caregiving activities, described as involvement, are affecting the caregivers' self-care behaviors.

CHAPTER IV

Methodology and Procedures

Overview

This study was designed to determine the relationship between the level of caregiver involvement and the self-care behaviors of the caregiver. In this chapter a description of the research design, the research question, operational definitions and concepts, reliability and validity of the instrument, subject selection, a description of the sample, data collection procedures, analysis of data, assumptions and limitations will be provided.

Research Design

Data for this study were collected as part of a caregiver research project (Caregiver Responses to Managing Elderly Patients at Home, grant number 1-386005984-A1, Given & Given, 1986) funded by the National Institute of Aging. The study was conducted over three years by the College of Human Medicine and the College of Nursing at Michigan State University. Within the longitudinal caregiver study a variety of data were collected in successive waves concerning differing aspects of the experience of caring for a debilitated family member. The involvement instrument was used through the successive waves, but the self-care behavior instrument was not introduced to the longitudinal study until Wave III. Wave III data, which were collected six months after the beginning of the longitudinal study, were used for this cross-sectional analysis. The self-care behavior instrument utilized in the longitudinal caregiver study included questions pertaining to caregiver self-care. Caregiver involvement data were collected by telephone or home interviews. Caregiver self-care data were collected through the use of self-administered mailed questionnaires. This study is only concerned with the two instruments utilized in the longitudinal study pertaining to involvement and self-care behaviors.

The longitudinal study began with 307 subjects. At Wave III 233 subjects remained as regular caregiver patient dyads. For various reasons, such as institutionalization of patient, death of patient, etc., the debilitated family member no longer required a caregiver. The majority of the subjects were female. The majority of caregivers were married and a large number of those were spouses of the patient. Almost all of the caregivers lived with the patient. Almost all of the caregivers and patients were Caucasian. The mean age of the patient was 78 years and the mean age of the caregiver was 62 years. Variables of concern are involvement and selected self-care behaviors.

Research Question

The research question is "What is the relationship between the level of caregiver involvement and the self-care behaviors of the caregiver?" From the conceptual framework, as discussed in Chapter Two, it can be noted that caregiver involvement constrains caregiver self-care agency, or the ability to perform self-care behaviors. As the level of caregiver involvement increases, the caregiver self-care agency will be adversely affected, which will ultimately affect the caregiver's self-care behaviors. From the conceptual model two hypotheses can be proposed.

Hypothesis 1: As the level of caregiver ADL involvement increases, caregivers will score lower in the areas of a) nutrition, b) exercise, c) sleep/rest and d) stress management on the self-care instrument.

Hypothesis 2: As the level of caregiver IADL involvement increases, caregivers will score lower in the areas of a) nutrition, b) exercise, c) sleep/rest and d) stress management on the self-care instrument.

Operational Definitions and Concepts

The variables utilized in this study are operationalized in the following manner:

1. Self-care - this concept is operationalized through examining the areas of self-care. (See Appendix C for an example of the instrument). A review of the literature indicates that there are many areas of self-care. Self-care can include: eye care, dental care, personal safety and smoking/use of drugs. It is beyond the scope of this study to examine all possible self-care behaviors. This study will focus on an examination of the self-care instrument of 39 items which appears to indicate several areas of self-care behaviors that are of interest to the study.

The self-care instrument, also known as the health habit scale, was developed by Given, Given and King (1982) from the work of Breslow and Sommers (1977). Breslow and Sommers noted that self-care behaviors change with time and so divided the life span into 10 periods. The self-care instrument was designed to examine the behaviors that were carried out by the respondents on their own behalf.

Given,et al. (1982) used approximately 150 subjects who were over 55 years old. Three response categories were used: "almost always" to "sometimes" to "never". An analysis from the study by Given, et al. was employed to investigate if items pertaining to sleep, diet, exercise or stress could be clustered into unidimensional self-care sub-scales. Not all areas of self-care were examined. The sub-scales displayed high mean scores and low standard deviations, which indicated that ceiling effects were involved. Given, et al. concluded that they were unable to cluster the responses into groups of self-care behaviors. Respondents reported confusion with some of the questions. The three point scale of the self-care instrument was possibly too narrow to distinguish variation in responses.

Powers-LaMoe (1988), using the same instrument as was used in this study, was able to identify five areas of self-care with a group of 120 caregivers caring for family members with Alzheimer's Disease. Those areas included physical-care, time-care, sleep-care, social-care and diet-care. The Cronbach's alpha or reliability for the sub-scales used in the study by Powers-LaMoe ranged from .51 to .74. In the study by Powers-LaMoe items from the self-care instrument tended to be in more than one self-care behavior area. This overlapping of self-care instrument items tended to diminish the argument that there were five distinct self-care behaviors being measured. Therefore, within this study the researcher will attempt to separate the self-care instrument items into non-overlapping self-care dimensions and establish internal consistency utilizing Cronbach's alpha.

When examining both the literature and the self-care instrument, there appear to be four main areas of self-care behaviors which include nutrition, exercise, sleep/rest and stress management. The literature indicates that the areas of self-care behaviors may impinge on each other. The four main areas of self-care behaviors were chosen because they were congruent with a portion of the core of Orem's (1980) self-care requirements. Milsum (1980) and the National Institute on Aging (1981) also identify these four areas as components of health. The items associated with each of the areas are reported in Table 1.

Self-care Behavior Scoring

A rating scale was constructed to score three levels of self-care. The possible responses consisted of: 1 - rarely do this, 2 - do this occasionally, and 3 - do this frequently. Sub-scales were established on the four areas, i.e., 1) nutrition, 2) exercise, 3) sleep/rest and 4) stress management, through factor analysis. A respondent's score on a sub-scale is equal to the mean of the scores on all items that comprise the sub-scale. The rationale for this is that each statement regarding a self-care behavior is considered to be a partial indication of the self-care area in question. By averaging the score an investigator will obtain a score closest to the "true" sub-scale score, because random response associated with individual items will be reduced. Higher scores on these sub-scales indicate self-care behaviors by the caregiver at a higher frequency and lower scores mean the caregiver is using these self-care behaviors less frequently.

Table 1

Self-care Behavior Items - Nutrition, Sleep, Exercise, Stress Management

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Nutrition

Item 1: "I eat a variety of foods including fresh fruit, raw vegetables, and whole grain breads or cereals."

Item 2: "I eat breakfast."

Item 3: "I drink six to eight glasses of water each day."

Item 4: "I limit the amount of animal fat, eggs, butter and cream that I eat."

Item 5: "I limit the amount of refined sugar, pastries and sweets that I eat."

Item 6: "I limit the amount of salt I eat and add to foods."

Sleep

Item 1: "I get between six and eight hours of sleep."

Item 2: "I have uninterrupted sleep."

Item 3: "I fall asleep easily at night without medication."

Exercise

Item 1: "I do vigorous exercise for 15-30 minutes (swimming, jogging, brisk walking, biking)."

Item 2: "In the course of your normal day, do you walk at least one continuous mile?"

Item 3: "Do you play golf, other sports, such as tennis or swimming."

Stress Management

Item 1: "I take some time for myself."

Item 2: "I attend support group metings."

Item 3: "I listen to TV or radio."

It should be noted that some of the questions on the self-care behavior instrument are written as outcomes when they should be written as goals. Examples are sleep, Item 2, which would be better if written as "I try to have uninterrupted sleep" and Item 3, "I try to fall asleep at night without medication." Although there are many ways an individual can cope with stress, it is beyond the scope of this study to determine all the means utilized to manage stress. Based on the judgement of the researcher, the five items listed in the stress management sub-scale will be treated as methods for coping with stress. (See Appendix C for the self-care instrument)

2. Family caregiver - an unpaid family member who will be providing assistance with ADL and IADL dependencies to the patient or debilitated family member (Given & Given, 1986).

3. Patient - that person who is the focus of care by the caregiver, is over 65 years old and is receiving assistance with two or more ADL or IADL dependencies from a family caregiver (Given & Given, 1986).

4. Involvement - this concept is operationalized as assistance provided to the debilitated family member by the caregiver in two distinct areas of activities (Given & Given, 1986). Each area of involvement will be known as either activities of daily living (ADL) or instrumental activities of daily living (IADL). These sub-scales were created for the longitudinal study. Wave I of the

longitudinal study had a Cronbach's alpha of .90 for the ADL scale and .78 for the IADL scale, which indicates these instruments are reliable (Given, Given, Cornwell, Stommel, King & Collins, 1987). ADL activities are those that need to be performed daily, such as eating, bathing and toileting. IADL activities are those that need to be performed but are of a lesser urgency. Examples of IADL include shopping, laundry and using the telephone. The involvement assessment instrument contains 16 questions regarding these areas, which are then grouped together to form sub-scales of each area. The items associated with each area are reported in Table 2.

A Likert scale was constructed to identify five levels of involvement for each ADL and IADL area. The scale used was 0 = does not help, 1 = caregiver helps once a week or less, 2 = caregiver helps several times a week (2-6), 3 = caregiver helps once a day, and 4 = caregiver helps several times a day. Scores of individual ADL and IADL items were added together for a total ADL or IADL score respectively. The added scores can be considered an overall indication of the frequency of involvement in ADL or IADL. A lower score indicates less involvement and a higher score indicates more involvement of the caregiver with the patient. (See Appendix D for the involvement instrument.)

Table 2

Involvement Items - Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL)

Activities of Daily Living (ADL)	
Item 1:	"How frequently do you help your relative with eating?"
Item 2:	"How frequently do you help your relative with dressing and undressing?"
Item 3:	"How frequently do you help your relative with combing hair or shaving?"
Item 4:	"How frequently do you help your relative with taking a shower or bath?"
Item 5:	"How frequently do you help with toileting or commode?"
Item 6:	"How frequently do you help relative with walking?"
Item 7:	"How frequently do you help with getting around the house?"
Item 8:	"How frequently do you help your relative get in or out of bed?"
Item 9:	"How frequently do you help clean patient from incontinence of urine?"
Item 10:	"How frequently do you help clean patient from incontinence of stool?"
Instrumental Activities of Daily Living (IADL)	
Item 1:	"How frequently do you help patient with shopping?"
Item 2:	"How frequently do you help your relative with the housework?"
Item 3:	"How frequently do you help your relative with laundry?"
Item 4:	"How frequently do you help your relative with cooking?"
Item 5:	"How frequently do you help your relative handle money?"
Item 6:	"How frequently do you help your relative arrange transportation?"

Reliability of the Involvement and Self-care Behavior Instruments

Reliability, as defined by Polit and Hungler (1983), is the degree to which an instrument measuring a specified attribute is free from random error. Powers-LaMoe (1988) demonstrated moderate to strong reliability of the self-care behavior sub-scales using internal consistency. Given, et al. (1987) were able to establish reliability of the ADL and IADL sub-scales through the use of internal consistency. According to Polit and Hungler, internal consistency is the degree to which all the subparts of an instrument are measuring the same attribute.

The measure of consistency used by Given, et al. (1987) and Powers-LaMoe (1988) is Cronbach's alpha. This measure has a range of 0.00 to 1.00, as long as the item total correlations are positive. The higher the number, the greater the internal consistency is for that instrument. According to Polit and Hungler (1983), a Cronbach's alpha greater than .70 is considered adequate to demonstrate reliability. To establish reliability for the self-care behavior and involvement sub-scales, this study will utilize Cronbach's alpha to establish internal consistency.

Validity of the Self-care Behavior and Involvement Instruments

Validity is the "degree to which an instrument measures what it is intended to measure" (Polit & Hungler, 1983, p. 624). One method to establish validity is through content validity. Content validity is defined as "the degree to which the items in an instrument adequately represent the universe of content" (Polit & Hungler, 1983, p. 611). This is usually determined by a panel of experts judging the instrument to be valid. Powers-LaMoe (1988) reported content validity of the self-care instrument was assumed. Because the self-care behaviors instrument was constructed by experts and has been assumed valid for the Powers-LaMoe study, this study will also assume the self-care behaviors instrument to have content validity. The involvement instrument of ADL and IADL can also be assumed to have content validity. Since the involvement instrument was developed by experts in their respective fields of study, the instrument can be assumed to be valid at this most basic level, namely content validity.

Another method to establish validity is through criterion validity. Polit and Hungler (1983) define criterion validity as how well the scores measured by an instrument correlate with a criterion set by the investigator. Pearson r is a method to determine if a correlation exists between two variables. The Pearson r, can range from -1.00 to +1.00. The "+" or "-" sign indicates a positive or negative relationship between the criterion and the variables under investigation. Therefore, in a positive relationship, high levels of the criterion are associated with high levels of the variables under investigation. In a negative relationship, high levels of the criterion are associated with low levels of the variables under investigation.

A major problem with establishing criterion validity is trying to find a criterion that is valid. As yet, neither the self-care behaviors instrument nor involvement instrument has established criterion validity.

Sample

Criteria for inclusion of caregivers for this study were: 1) the patient must have been 65 years or older, 2) had at least one chronic illness, 3) had a health state that required care for three or more months, 4) was receiving assistance with two or more ADL or IADL dependencies and 5) had a primary caregiver who provided care to the patient. The caregiver had to live in the state of Michigan and volunteer for this study.

Data Collection Procedures

Caregivers of debilitated family members were identified through community agencies, homecare agencies and Visiting Nurses Associations. Letters were sent to caregivers requesting their participation in the longitudinal caregiver study. Caregivers who were willing to participate returned to the study center self addressed post cards. During intake interviews participants were contacted by telephone by research staff and prescreened to ensure that caregivers met inclusion criteria. Caregivers were contacted on initial intake interviews followed by Waves I through III. Data were gathered during each Wave for the longitudinal caregiver study.

The data for the caregiver study were collected in two ways: A self-administered questionnaire, which included the self-care behavior instrument, was sent to the caregiver to be completed and returned. An interview with a second questionnaire which included the involvement instrument was conducted by telephone or in the home. Wave III was the first Wave in which both the self-care instrument and the involvement instrument were utilized. The interviewers included graduate students from Michigan State University's College of Nursing and other graduate programs at Michigan State University. Interviewers were trained over a period of two days. Topics covered in interview training included an overview of the research project, ethical considerations in data collection and interviewing techniques (Collins, Given, Given & King, 1988). The interviewers administered the questionnaires to 233 caregivers during Wave III of the study.

Human Subjects

The rights of the caregivers were protected by maintaining the standards of the Michigan State University's Committee on Research Involving Human Subjects. As described previously, all caregivers were mailed a letter describing the study and requesting caregiver participation. The letter described the study and assured the caregiver of confidentiality.

Caregiver subjects were contacted and screened for suitability of inclusion. Those caregivers who were deemed suitable for inclusion in the study were contacted for an intake interview. During this interview, the interviewer described the purpose of the study and assured the caregiver that he or she was free to withdraw from the study at any time. The caregiver was sent a consent form along with the self-administered questionnaire to be signed and returned. (Refer to the consent letter in Appendix B) Confidentiality was assured in the consent form.

Analysis of Data

The research question, and hypotheses 1 and 2 were designed to determine if a relationship exists between involvement and self-care behaviors. Both hypothesis 1 and hypothesis 2 will be analyzed using the same data method. One method of analysis to determine if this hypothesized relationship exists is through correlation analysis. Correlation analysis, according to Polit and Hungler (1983), is conducted in order to determine if variables are related to each other.

A correlation between two variables can be represented as a scatter plot that is plotted against the X,Y axes. The resulting configuration is known as a scatter plot, which can give the researcher information on the direction and strength of the relationship between variables. To aid the researcher in interpreting a scatter plot, a correlation can be calculated in which a numerical value can range from -1.00 to +1.00. A perfect relationship between variables will be +1.00 or -1.00 with the "+" or "-" indicating a positive or negative relationship between variables. No correlation between variables is noted as 0.00. The most prevalent correlation analysis utilized is the product moment correlation, also known as the Pearson r (Polit & Hungler, 1983). This researcher will also employ the Pearson r for data analysis. Based on the researcher's knowledge of the conceptual framework from Chapter Two and the review of the literature in Chapter Three, a negative correlation between ADL and involvement and between IADL and involvement is expected.

The significance of the relationship between self-care behaviors and involvement is determined by first computing an F value. The F value is determined by comparing the variance due to involvement with the variance due to chance or error. If the F value is significant, then the relationship between self-care behaviors and involvement is significant. For this study, the .05 significance level will be used.

Assumptions

1) Subjects in this study are aware of their activities in self-care and can report the extent to which they perform such behaviors.

2) Subjects are aware of their activities associated with caregiving and can report their involvement in these activities.

3) Self-reports on caregiver involvement and caregiver self-care behaviors are accurate and valid measures of the concepts of caregiver involvement and caregiver self-care behaviors.

Limitations

1) This study will examine only selected self-care behaviors and types of involvement and not the full range possible.

2) The tools to be used have limited reliability and therefore may contain a large amount of error variance.

3) Caregivers selected for this study may not be representative of caregivers as a whole, therefore results of this study may not be generalized to all caregivers.

4) While self-care may be affected by other related concepts such as locus of control, health beliefs or health status, this study is limited to examining how self-care behaviors are related to involvement.

5) Data for this study were not gathered by this study's principle investigator, and therefore are considered a secondary analysis.

Summary

In Chapter IV a discussion of methodology was presented. A number of major areas of discussion were covered. The research is a cross-sectional study utilizing data collected from a larger caregiver research project. A research question was presented relating to self-care behaviors of family caregivers and caregiver involvement. From this research question two hypotheses were proposed.

Operational definitions were given for self-care, family caregiver, patient and involvement. A discussion of the sample was presented. Discussions of the involvement scale and the self-care scale were presented. Data collection procedures were explained. Analysis of the data will be addressed in Chapter Five.

CHAPTER V

Data Presentation and Analysis

Overview

The analysis of the data will be discussed in Chapter Five. The research question, "what is the relationship between the level of caregiver involvement and the self-care behaviors of the caregiver?", will be addressed. The results of the data analysis will be described. The following results will be presented: sample characteristics, a description of the self-care behavior sub-scales, measures used to establish reliability and validity of the self-care behavior sub-scales, a description of the involvement sub-scales, measures used to establish reliability and validity of involvement sub-scales, the relationship between involvement and self-care behaviors.

Description of the Sample

The following is a description of the information found in Tables 3 and 4. The sample consisted of 233 caregivers, of which 40 (17%) were male and 193 (83%) were female. There were 116 male (50%) and 117 female (50%) patients. Age of the caregivers ranged from 27 to 84 years with a mean

Table 3

Demographic Data - Range, Mean, Standard Deviations of Caregiver Age, Patient Age, Adjusted Household Income, Hours of Care and Duration of Care

Variable	Range	Mean	Standard Deviation	N
Caregiver Age	27 yrs - 84 yrs	62.00	11.38	233
Patient Age	63 yrs - 99 yrs	78.00	8.83	233
Adjusted household income (yearly)	$ 2,250 - 73.248	$15,757	$10,710	227
Hours of care caregiver provides	1 - 24 hrs	10.84	7.87	231
Duration of caregiving (years)	0 - 40 yrs	5.30	6.75	232

Table 4

Demographic Data - Number and Percent of Caregiver and Patient Gender, Caregiver and Patient Race, Family Relationship, Caregiver Education, Medical Reason for Caregiving, Caregiver and Patient Health (N=233)

Variable	Category	Numbers	Percent
Caregiver gender	male	40	17
	female	193	83
Patient gender	male	116	50
	female	117	50
Caregiver race	Caucasian	214	92
	Black	17	7
	Hispanic	1	.43
	Am. Indian	1	.43
Patient race	Caucasian	214	92
	Black	18	8
	Hispanic	1	.43
Family relationship of caregiver to patient	Spouse	127	55
	Daughter/son	79	34
	Daughter-in-law/ son-in-law	14	6
	Sister/sister-in-law, brother/ brother-in-law	5	2
	Other relative	8	3
Caregiver education	Grade school or less	16	7
	Some high school	34	15
	High school graduate	58	25
	Some college	79	34
	College graduate	22	9
	Graduate or professional	24	10

Table 4 (continued)

Variable	Category	Number	Percent
Medical Reason for Caregiving (N=232)	Heart disease	20	9
	Emphysema	5	2
	Diabetes	7	3
	Arthritis	6	3
	Stroke	71	31
	Cancer	11	5
	Alzheimer's	26	11
	Old age	18	8
	Fractured hip	9	4
	Post-op complications	7	3
	Alcoholism	2	1
	Parkinson's	19	7
	Blindness	3	1
	Quadraplegic/ paraplegic	4	2
	Multiple sclerosis	5	2
	Depression	1	.43
	Retarded	1	.43
	Other	20	9
Caregiver health	Excellent	35	15
	Good	139	60
	Fair	53	23
	Poor	6	3
Patient health	Excellent	12	5
	Good	76	33
	Fair	87	37
	Poor	58	25

age of 62 years. Patient age ranged from 63 to 99 years with a mean age of 78 years. Caregiver race was composed of 214 Caucasian (92%), 17 Black (7%) and one each Hispanic and American Indian (.43% each). Almost all patients were Caucasian (214 or 92%) with 18 Blacks (8%), and one Hispanic (.43%) The caregivers' relationship to the patient were primarily spouses, 127 (55%), and adult children, 79 (34%).

The educational level of the caregivers ranged from less than grade school to graduate or professional level. Sixteen caregivers (7%) went to only grade school, thirty four caregivers (15%) had some high school education, fifty eight caregivers (25%) graduated from high school and seventy nine caregivers (34%) had some college education. Finally, twenty two caregivers (9%) graduated from college and 24 caregivers (10%) had completed graduate or professional education.

Caregivers were providing care to patients for a variety of medical reasons. The most frequent medical diagnoses included heart disease (9%), stroke (31%), Alzheimer's disease (11%) and old age (8%).

The health of the caregivers was reported as excellent (15%) or good (60%). Only 26 percent of caregivers reported their own health to be fair or poor. Only twelve (5%) patients were classified by caregivers as being in excellent health, with the majority being ranked as good (33%), fair (37%) and poor (25%).

Annual household income was adjusted for the number of people in the household. Household income ranged from a low of $2,250 to a high of $73,248. Mean income was $15,757. The standard deviation was $10,690.

The hours of care the caregiver provided per day ranged from one hour to 24 hours. The mean was 10.8 hours with a standard deviation of 7.87 hours. The duration of caregiving (in years) ranged from 0 to 40 years with a mean of 5.30 years and a standard deviation of 6.75.

In summary, the caregivers tended to be younger than the patients and the majority of caregivers were female. Most of the caregivers and patients in the study were Caucasian. Spouses made up the largest group of caregivers and most of the caregivers had at least a high school education. There were a variety of primary diagnoses, but no one diagnosis accounted for more than half of the cases. The majority of caregivers rated their own health as good to excellent. Caregivers rated patient's health as good to fair. Adjusted income had a wide range. Caregivers averaged about 10 to 11 hours of care per day.

Description of the Self-care Behaviors Sub-scales

An attempt was made to create four sub-scales from the self-care behaviors and involvement instruments. Items were assigned to self-care behavior sub-scales according to the judgement of the investigator. The assignment of items to self-care behaviors was based on the investigator's understanding of the conceptual model discussed in Chapter II and the review of the literature in Chapter III. Four sub-scales were constructed. A summary of the items in the sub-scales can be found in Table 5.

The nutrition sub-scale was composed of six items. The scale mean was 2.43. The item means ranged from 2.00 to 2.84. Five out of six scale items were greater than 2.36 indicating that most caregivers tended to perform these self-care behaviors more often than occasionally. The item means indicate that the scale item responses are skewed toward performing these self-care behaviors regularly. Item standard deviations ranged from .45 to .81. According to Polit and Hungler (1983), standard deviation is a measure of the average variation of individual responses from the item mean. Items with low standard deviations indicate that answers are more homogenous or that respondents tended to answer the item the same way. Item 1 of the nutrition sub-scale has a relatively low standard deviation of .45, which indicates that the item responses tended to be clustered around item means, or that most respondents tended to give the same response. Item total correlations ranged from .28 to .54. Polit and Hungler state that scale items need to be positively correlated and have item total correlations no smaller than .20. All items are positively related to each other with sufficient item total correlation. (See Table 5 for sub-scale summaries).

Table 5

Description of Self-care Behavior Sub-scales - Item Means, Standard Deviation, Item Total Correlation, Scale Mean, Cronbach's Alpha

Item Number	Mean	Standard Deviation	Item Total Correlation	Scale Mean	Cronbach's Alpha
		Nutrition			
1 eat variety of foods	2.84	.45	.30		
2 eat breakfast	2.61	.69	.24		
3 drink water	2.00	.81	.28		
4 limit fat	2.42	.80	.54		
5 limit sugar	2.37	.77	.48		
6 limit salt	2.54	.73	.43		
				2.43	.66
		Sleep			
1 sleep 6-8 hours	2.52	.72	.49		
2 uninterrupted sleep	1.98	.84	.41		
3 sleep without medication	2.60	.71	.44		
				2.37	.64
		Exercise			
1 vigorous exercise	1.61	.81	.43		
2 walk 1 mile	1.65	.79	.26		
3 golf, tennis,swimming	1.34	.66	.27		
				1.53	.49
		Stress Management			
1 take time for self	2.08	.75	.20		
2 attend support group	1.43	.70	.10		
3 listen to TV, radio	2.77	.46	.13		
4 read	2.63	.59	.25		
				2.12	.35

The sleep sub-scale contained three items with a scale mean of 2.37 and item means that ranged from 1.98 to 2.60. The means of items 1 and 3 are greater than 2.50 indicating that caregivers performed these two self-care behaviors more often than occasionally. The item means indicate that the scale item responses are skewed toward caregivers performing these self-care behaviors regularly. Item standard deviations ranged from .71 to .84. Item total correlations ranged from .41 to .49. This indicates moderate relationships between scale items. (See Table 5 for sub-scale summaries).

The exercise sub-scale consisted of three items. The scale mean was 1.53 and the item means ranged from 1.34 to 1.65 with items 1 and 2 having a mean greater than 1.50. The item means indicate that the scale responses are skewed toward caregivers performing these self-care behaviors rarely to occasionally. Item standard deviations ranged from .66 to .81. Item total correlations ranged from .26 to .43. This indicates fairly low correlations among items. (See Table 5 for sub-scale summaries).

An attempt was made to create a stress management sub-scale in which there were four items with a scale mean of 2.12 and the item means ranged from 1.43 to 2.77. Items 3 and 4 had means greater than 2.50, which tends to skew the answers toward performing these self-care behaviors regularly. Standard deviations ranged from .46 to .75. Item 4 had a standard deviation of .46, which indicates that the item responses tended to be clustered around item means, or that the respondents tended to give the same response. Items 1 and 4 have item total correlations of .20 and .25. However, items 2 and 3 have item total correlations of .10 and .13 which indicate they are hardly related to items 1 and 4. This may be due to the numerous ways in which people deal with stress. Also, the proposed sub-scale items may not necessarily be used specifically by the caregiver for dealing with stress. The caregiver may be using the items on the stress management scale as a means for recreation. Scale items were probably not specific enough to measure stress management. A much larger and more specific scale would probably be needed to measure stress management. Because it would not be meaningful to use a scale with only 2 items, the stress management sub-scale will be eliminated from further consideration and analysis in this study.

To summarize, the item means on the proposed self-care behaviors sub-scales tend to indicate a skewed distribution. This skewed distribution and limited variance on some of the items indicate that ceiling effects are present. When a ceiling effect is present often insufficient variation in item responses occurs (Polit & Hungler, 1983). The ceiling effect may be due to the sample being homogenous in its composition. Skewed distribution of responses and ceiling effect indicate that the scales have inherent weaknesses when measuring the concepts of nutrition, sleep and exercise.

Reliability and Validity of Self-care Behavior Sub-scales

Content validity was assumed to have been established in this study because the self-care behaviors instrument was developed by experts in their respective fields. Trying to establish criterion validity is difficult. An appropriate predictor variable has not been found, therefore, criterion validity has not been established.

Cronbach's alpha is used to establish reliability. Cronbach's alpha, which can range from 0.00 to 1.00, as long as all the item total correlations are positive, demonstrates the degree of reliability a sub-scale possesses. According to Polit and Hungler (1983), a Cronbach's alpha of at least .70 is considered adequate in establishing reliability. Polit and Hungler have also noted that a Cronbach's alpha of less than .30 indicates that a sub-scale possesses reliability that is too low to be of any value. The Cronbach's alphas for the following self-care behaviors sub-scales were: nutrition, .66; sleep, .64; exercise, .49 (see Table 5). In the opinion of the researcher, these sub-scales would be considered to have a moderate level of reliability.

There is more confidence in the nutrition and sleep sub-scales than in the exercise sub-scale in regards to reliability. However, reliability for the self-care behaviors sub-scales is considered moderate.

To summarize, when considering the data for the scale construction as well as the validity and reliability data, the self-care behavior sub-scales at best could be considered moderate measures of nutrition, sleep and exercise. One reason the sub-scales may be moderate could be the homogeneity of responses.

Description of Involvement Sub-scales

The items for the ADL sub-scale and the IADL sub-scale may be found in Table 2. The ADL sub-scale contained 10 items with a scale mean of 1.48 and item means that ranged from .96 to 2.37. Item means indicate that responses were skewed toward "once a week or less" and "several times a week". Item standard deviations ranged from 1.23 to 1.86. Item means indicate the item responses varied widely from item to item, and standard deviations indicate that there was also substantial variation in responses for each individual item. Item total correlations ranged from .35 to .75. Because all item correlations were greater than .20, this indicates an acceptable degree of relationship between the items. The IADL sub-scale consisted of six items with a scale mean of 1.88 and item means that ranged from 1.04 to 3.31. Item means indicate the responses were skewed toward "once a week or less" and "several times a week". Item standard deviations ranged from .72 to 1.38. Item means indicate the item responses varied widely and with the exception of item 1, standard deviations indicate that responses were not clustered around the item means. Item total correlations ranged from .13 to .54. Items 1 through 5 correlate with each other. Item 6 does not correlate sufficiently well with the other items. (See Table 6 for sub-scale summaries.)

In summary, the item means for the ADL and IADL sub-scales were skewed. The standard deviations generally indicate the item responses are scattered widely around the item means. The ADL items all correlate at least moderately well with each other. In the IADL sub-scale, Item 6 correlated very weakly with the other sub-scale items. At this point Item 6 will remain in the IADL sub-scale until the reliability data is further examined.

Validity and Reliability of Involvement Sub-scale

Content validity was assumed because the instrument used in this study was constructed by experts in their respective fields. Another method used to establish validity is through criterion-related validity. This is established by demonstrating the degree of relationship between a criterion variable and the scale being established (Polit & Hungler, 1983). It is difficult to discover a

Table 6

Description of Involvement Sub-scales - Item Means, Standard Deviation, Item Total Correlation, Scale Mean, Cronbach's Alpha

Item Number	Mean	Standard Deviation	Item Total Correlation	Scale Mean	Cronbach's Alpha
Activities of Daily Living (ADL)					
1 help eat	1.49	1.86	.49		
2 help dress	2.37	1.75	.71		
3 help shave	1.55	1.57	.58		
4 help bathe	1.63	1.23	.53		
5 help toilet	1.62	1.84	.75		
6 help walk	1.18	1.73	.35		
7 help ambulate	1.26	1.80	.53		
8 help in/out of bed	1.61	1.83	.70		
9 help incontinence/urine	1.11	1.56	.53		
10 help incontinence/stool	.96	1.31	.51		
				1.48	.86
Instrumental Activities of Daily Living (IADL)					
1 help shop	1.52	.72	.42		
2 help housework	2.47	1.28	.44		
3 help laundry	1.62	.96	.41		
4 help cooking	3.31	1.38	.54		
5 help money	1.35	1.00	.24		
6 help transportation	1.04	1.00	.13		
				1.88	.62

criterion that can be used for both of these sub-scales. An appropriate predictor variable has not been found; therefore, criterion validity has not been established.

Cronbach's alpha was employed to determine if reliability for the ADL and IADL sub-scales could be established. The Cronbach's alpha for ADL was .86 and for IADL was .62 (see Table 6). Reliability has been established for the ADL sub-scale but reliability for the IADL sub-scale has not been firmly established.

As was previously noted in the discussion of the IADL sub-scale, Item 6 did not correlate sufficiently highly with the other items in the sub-scale (see Table 2 for involvement items). One possible explanation for the limited relationship between Item 6 (arranging transportation) and the other items is that caregivers are not often involved in arranging transportation; therefore, Item 6 may not be linked to IADL. The scale could be improved by eliminating Item 6. When the ADL sub-scale was tested for reliability using Wave I data of the longitudinal caregiver study (N=307), the reliability was .78. Although Item 6 does not statistically belong with the other items, in the judgement of the investigator, the 6 IADL items appear to represent elements of IADL. Therefore, Item 6 will remain in the IADL sub-scale.

Since the IADL sub-scale is under development, it needs to be tested using different samples in order to establish its reliability. If the IADL sub-scale was to be used only for this study, Item 6 would be eliminated to improve the sub-scale. However, since reliability is in the process of being established for this sub-scale, it is defensible to leave all the items on the scale. This would allow for determining reliability using different samples. Therefore, the best that could be said for the IADL sub-scale is that although there is some reliability, it is moderate. The IADL sub-scale will be utilized in this study even though reliability is moderate.

To summarize, analysis of the ADL sub-scale reveals that validity is assumed and that the reliability is strong in terms of consistency. This indicates that the sub-scale is a good measure of ADL. With the exception of Item 6, the reliability of the sub-scale for IADL is moderate.

Relationship Between Involvement and Self-care Behaviors

The research question, "what is the relationship between the level of caregiver involvement and the self-care behaviors of the caregiver?", will be answered in this section. Because the stress management sub-scale has been eliminated from the study, hypothesis one is restated "as the level of caregiver ADL involvement increases, caregivers will score lower in the areas of a) nutrition, b) exercise and c) sleep/rest on the self-care instrument" and hypothesis two is restated "as the level of caregiver IADL involvement increases, caregivers will score lower in the areas of a) nutrition, b) exercise and c) sleep/rest on the self-care instrument".

When self-care behaviors were correlated with the ADL measure, the following Pearson r values were noted: nutrition, r = -.095, exercise, r = -.239 and sleep, r = -.134. There is no significant relationship between nutrition and ADL. A significant relationship exists between exercise and ADL and between sleep and ADL. All three self-care behavior sub-scales demonstrated a negative relationship with ADL, but only the relationship between ADL and exercise and sleep were statistically significant (see Table 7 for summaries).

In summary, the first hypothesis is accepted with respect to the effect of ADL on exercise and sleep self-care behaviors because a weak negative relationship has been established.

When self-care behaviors were correlated with the IADL measure, the following Pearson r values were noted: nutrition, r = -.055, exercise, r = -.170 and sleep, r = -.138. A significant relationship exists between exercise and IADL and between sleep and IADL. All three self-care behavior sub-scales demonstrated a negative relationship with IADL, but only exercise and sleep were statistically significant (see Table 7 for summaries).

In summary, the second hypothesis is accepted with respect to the effect of IADL on exercise and sleep self-care behaviors because a weak negative relationship has been established. To answer the research question, "what is the relationship between the level of caregiver involvement and the self-care behaviors of the caregiver?", it can be noted that the relationship between involvement and nutrition has not been demonstrated. A relationship exists between involvement and sleep and involvement and exercise.

Table 7

Pearson r Correlation of ADL and IADL and Self-careBehaviors of Nutrition, Exercise, Sleep (N=233)

	Pearson r	
	ADL	IADL
Nutrition	-.095	-.055
Exercise	-.239*	-.170*
Sleep	-.134*	-.138*

* = significance @ p = <.05

It could be postulated that involvement may affect only selected caregiver self-care behaviors.

Summary

Three self-care behavior sub-scales were created: nutrition, sleep and exercise. All three sub-scales had moderate levels of reliability. Criterion validity was not established for the involvement or self-care berhavior sub-scales. Two involvement sub-scales were used: ADL and IADL. The ADL sub-scale had strong reliability. The IADL sub-scale had moderate reliability. When examining the relationship between involvement and all the self-care behaviors, a negative pattern was noted. However, when examining involvement and the self-care behaviors of exercise and sleep, a significant correlation was demonstrated. Hypotheses 1a and 2a were not accepted. Hypotheses 1b,c and 2b,c were accepted (see Table 8 for summary of findings).

In Chapter Six a summary and implications for future research will be included. The manner in which the findings of this study may impact on the Clinical Nurse Specialist's practice will also be discussed.

Table 8

Summary of Findings - Hypotheses 1 and 2

	Accept	Not Accept
Hypothesis 1:		
As the level of caregiver ADL involvement increases, caregivers will score lower in the areas of:		
a) nutrition		X
b) exercise	X	
c) sleep	X	
on the self-care behavior instrument.		
Hypothesis 2:		
As the level of caregiver IADL involvement increases, caregivers will score lower in the areas of:		
a) nutrition		X
b) exercise	X	
c) sleep	X	
on the self-care behavior instrument.		

CHAPTER VI

Summary and Conclusions

Overview

In Chapter Six, conclusions drawn from the study will be discussed. Nursing theory as it relates to this study and scale development will also be discussed. In Chapter Six, the role of the Clinical Nurse Specialist in primary care as it is related to this study will be examined. Directions for the education of the Clinical Nurse Specialist will be also be explored. Finally, implications for research and future research will be discussed.

Conclusions

When investigating the relationship between involvement and self-care behaviors, a pattern of negative coefficients was observed for all self-care behaviors. Significant relationships between involvement and exercise and involvement and sleep were also demonstrated. Because all relationships between involvement and self-care behaviors were negative, it could be inferred that involvement in general affects self-care behaviors negatively. However, because only two of the self-care behaviors were affected significantly by involvement, it could be concluded that not all self-care behaviors will be significantly affected by involvement. Because a negative pattern between involvement and self-care behaviors was demonstrated, it could be concluded that caregivers are having trouble performing self-care behaviors as their involvement with the debilitated family member increases. Allowing caregivers time away from their caregiving duties could provide the caregivers with time to care for themselves. One way to provide caregivers with time away from their duties is through respite care.

In general, the scales utilized in this study were found to be moderate measures of the concepts they represented. This could be due to a limited number of items on the scales and homogeneity in responses. In order to determine if the relationship between involvement and specific self-care behaviors remains significant, better measurement of self-care behaviors will need to be developed. Measurement of stress management was unable to be achieved due to the proposed stress management sub-scale being psychometrically unsound. The proposed stress management sub-scale was therefore dropped. Findings and conclusions of this study will be discussed in the areas of nursing theory, scale development, the CNS in primary care, direction in education for the CNS and future research.

Nursing Theory

The implementation of Orem's theory proved to be a challenge in that Orem's theory was originally developed to be applied to nursing care in acute care settings. It was found that the theory could be adapted for primary care settings. To promote the understanding of Orem's theory it is recommended that development of conceptual definitions such as self-care agency be further refined. Self-care agency, as defined in Chapter Two, is the ability to react to self-care demands. This definition could be further refined by stating it as "the ability to make decisions pertaining to self-care behaviors." A third way of defining self-care agency would be "the ability to make decisions pertaining to the caregiver's health." Self-care agency was examined as a one time measure. Since caregiving is not a static role but a dynamic role, researchers need to test Orem's theory to determine if it will apply to the caregivers as their roles evolve across the caregiving trajectory.

According to the proposed nursing theory, as involvement affects caregiver self-care agency the caregiver's self-care behaviors will be affected. This was found to be true for involvement and the self-care behaviors of exercise and sleep. The nursing theory model needs modification to take into account any possible changes in involvement over time, such as improvement of the debilitated family member's status or institutionalization of the debilitated family member. The caregiver's self-care agency could be further affected by other variables. Future researchers may wish to identify modifiers or variables that are intrinsic or extrinsic to the self-care agency.

Intrinsic variables to self-care agency are those variables that comprise the caregiver self-care agency, such as caregiver age and health state. More research is needed to determine the different intrinsic variables that affect self-care agency. The implication for this is that some intrinsic variables may have more effect than other intrinsic variables on self-care agency. Extrinsic variables to self-care agency are those variables that may have an effect on caregiver self-care agency and ultimately on caregiver self-care behaviors. The extrinsic variable to self-care agency tested was involvement as a point in time. More study is needed to determine how involvement affects self-care behaviors as the caregiver's involvement changes over time. Other examples of extrinsic variables to self-care agency that could be included in a proposed model could include caregiver duration of care, employment of the caregiver, finances of the household, time spent caring, injury to the caregiver or death of the debilitated family member. The model used for this study is presently inadequate to study caregiving beyond a point in time.

The model for study needs to be expanded to take into account the caregiving experience over time and other variables that may impact self-care behaviors. These extraneous variables could be studied for their separate effect or combined effect on how they have an impact on caregiver self-care behaviors.

Because a negative pattern between involvement and selected self-care behaviors was noted, it could be argued that caregivers do not function well as their own self-care agent. However, caregivers rated their health as good to excellent. This may indicate a low score in a particular self-care behavior may not have a dramatic effect on the caregiver's overall health. Even though specific self-care behaviors are significantly affected by involvement, it could be hypothesized that when the total effect of caregiver self-care behaviors is considered, the net effect could be a caregiver who is able to maintain her or his health at a good to excellent level. Because caregivers could end up with a self-care deficit, caregivers need health care professionals such as the Clinical Nurse Specialist to help them overcome the self-care deficit.

When examining caregiver self-care behaviors, this researcher was attempting to gain insight into the health of the caregiver. Powers-LaMoe (1988) and Given, Given and King (1982) have previously noted that researchers may not be able to develop scales that measure specific self-care behaviors. Therefore, the study model could be modified to include the number of days in a specified time period caregivers felt ill. In this way the researcher would be able to determine how ill or healthy caregivers perceived themselves to be. Caregivers may have disabilities or single/multiple chronic illnesses such as hypertension or arthritis. Because the caregiver lives with these conditions every day, the caregiver may not view these conditions as illnesses. Therefore, knowing the number of days a caregiver feels ill allows the caregiver to define illness and relative health. How a caregiver perceives their health may be an indirect measurement of how well a caregiver is engaging in all caregiver self-care behaviors. This researcher would use the proposed study model again, but with self-care agency redefined and utilizing the number of days the caregiver feels ill instead of caregiver self-care behaviors. The model would also be expanded to include additional extrinsic variables besides involvement.

Scale Development

This study has attempted to develop sub-scales for involvement and self-care behaviors. Validity has yet to be empirically demonstrated. Criterion validity, as defined by Polit and Hungler (1983), remains as one method for establishing validity. When developing scales a researcher must keep in mind how validity will be established. Therefore, as a proposed scale is developed, specific criteria must be considered simultaneously. If validity is to be established through determining the degree a criterion variable correlates with a scale, then data on a criterion variable can be gathered simultaneously with data on a proposed scale. This would encourage the researcher to develop rationale for utilizing the criterion variable as a measure for validity before any data was gathered.

One reason reliability was not as high as hoped for on most of the scales was the small number of items per scale. Increasing the number of items per scale should increase the reliability. New items added must correlate well with existing scale items. Examples of items that could be added to the nutrition scale are "I read food labels to determine the nutritive value" and "I snack between meals". Examples of items that could be added to the sleep scale are "I feel rested and full of energy when I awaken in the morning" and "I need to nap in the middle of the day to catch up on my sleep". Examples of items that could be added to the exercise scale are "I attend aerobics class at least once a week" and "I walk instead of driving the car whenever possible".

Since self-care behaviors are initiated and performed by the caregiver for their own behalf, scale items need to be written as goals rather than outcomes. Rather than state "I have uninterrupted sleep", the item should be restated as "I try to get uninterrupted sleep." The self-care behaviors scales had low to moderate levels of reliability. Therefore, any significant relationship found between involvement and the self-care behaviors could be due to factors other than the self-care behaviors.

Internal consistency was used for determining reliability of the involvement sub-scales. According to Polit and Hungler (1983), internal consistency is the degree to which all the subparts of an instrument are measuring the same attribute. Internal consistency is employed because it requires only one examination of the instrument. Utilizing internal consistency as a reliability test allows the researcher to examine measurement error that may be due to the items selected for the instrument.

Few studies have been conducted on the self-care behaviors of the elderly. Therefore, scales need to be developed that specifically examine the self-care behaviors of the elderly. Since chronic illnesses tend to manifest themselves with the elderly, future self-care behavior scales for the elderly should include chronic illness. Scales could also include the use of alcohol, drugs and tobacco, dental care, podiatry care and dealing with grief/death.

The failure to establish a stress management scale probably was due to the numerous methods employed by caregivers to reduce stress. Some of the items on the proposed stress management sub-scale, such as reading, may have been used by the caregiver for recreational purposes rather than stress management. Conducting a survey in which caregivers report methods for managing their stress would guide the researcher in developing a stress management scale.

Another avenue to approach how caregivers deal with stress is by developing a scale of methods of relaxation. In this way if a caregiver has some means to relax, then the researcher would be indirectly measuring how the caregiver is dealing with stress. If a stress management/methods of relaxation scale were to be developed, a much larger scale would be required. In addition, the conceptual definition of stress management would need to be further developed so that the definition would be very specific. When a scale is proposed the scale items would more likely be highly correlated due to the items being specific to the concept of stress management. When developing a scale, an investigator would need to look for items that have moderate to high correlation with each other. Also, items that are chosen to be part of the scale need to fit with the concept of stress management. This should lead to a scale with higher reliability. The scale would need to be tested using different caregiver populations to determine if the stress management/methods of relaxation scale is measuring this concept. If the constructed scale was truly measuring stress management/methods of relaxation, then reliability should remain high regardless of the elder population.

CNS in Primary Care

Orem (1980) indicates that when a caregiver has a self-care deficit the caregiver will need assistance from a health care professional such as a Clinical Nurse Specialist (CNS). The CNS will be assisting the caregiver through the Supportive - Educative system. Haug (1985) states that the United States government needs to develop policies for caregivers to assist them financially as well as providing relief, such as respite care, from the increasing demands placed on them. Van Ort and Woodtli (1989) found there was a need for programs to support caregivers in order to help the caregivers maintain their health. If the CNS notes a self-care deficit in the area of sleep or exercise, a strategy to support the caregiver would be through arranging respite care. Miller, Gulle and McCue (1986) define respite care as a short term interlude in which a caregiver is allowed to relinquish his or her caregiving duties and care for his or her own needs. When a caregiver has a break from caregving duties, the caregiver would be able to catch up on his or her sleep or go for a walk. If a caregiver experiences a deficit of inadequate nutritional intake, the CNS could assist in arranging for a program such as Meals on Wheels to increase the availability of nutrition.

It is the goal of the CNS to increase the independence of the caregiver. When the CNS arranges for a service for the caregiver with a self-care deficit, the caregiver learns little about increasing their ability to make self-care behavior decisions. Therefore, in order to promote caregiver independence and self-care behavior decision making ability, the CNS must educate and assist the caregiver to learn how to access appropriate community agencies. As a strategy to assist the caregiver in achieving greater independence, the CNS could first use a directory, with the names of contact persons, of the available community agencies. This directory would then be distributed to caregivers. The CNS would initially assist the caregiver with contacting agencies for desired services. The caregiver would then be encouraged to make agency contacts for themselves.

Another strategy for the CNS to serve the caregiver is by assessing self-care behaviors in which the caregiver is engaging and how well the caregiver is performing these self-care behaviors. The CNS could then teach the caregiver how to increase the caregiver's performance in the specific self-care behavior. In this way caregivers would be doing more for themselves in order to promote their independence. From Table 5 in Chapter Five, it was noted that caregivers at best get occasional uninterrupted sleep. One strategy for improving sleep quality is to teach the caregiver how to arrange for temporary care for the patient so that the caregiver can get uninterrupted sleep. The caregiver could be taught to develop a network of temporary caregivers from family, friends or agencies. When observing Table 5, it can also be noted that in the self-care behavior of exercise, the caregiver performed the scale items less than occasionally. Again, teaching the caregiver to establish a network of temporary caregivers will allow the caregiver time to engage in exercise. The CNS could teach the caregiver to incorporate exercise into the caregiver's daily routine. This may include several sessions of five minute exercise routines that are performed throughout the day rather than a single block of time.

There are many self-care behaviors that were not specifically examined in this study. However, the caregiver could still experience self-care deficits when not engaging in these self-care behaviors. An example would be if a caregiver were experiencing stress overload and social isolation as self-care deficits, then referring him or her to, or starting a caregiver support group, would be a means for the CNS to assist the caregiver in overcoming these self-care deficits. If the caregiver was unable to get away to a support group, the CNS could teach stress management techniques such as meditation/prayer or teach the caregiver time management in order to arrange for quiet time for the caregiver. Self-care behaviors that elderly caregivers may need to engage in are early detection of disease processes, such as a lump in the breast or a change in bowel habits, which could indicate the presence of cancer. Diabetic caregivers would need to be able to monitor their blood sugar and adjust their insulin accordingly. Still another self-care behavior that caregivers need to be taught and/or reinforced is to return to the clinic for reevaluation by the CNS if the caregiver is unable to control a disease process. For example, a caregiver that is diabetic with consistently elevated blood sugars would need to return to the clinic rather than wait for a diabetic reaction to occur that could incapacitate the caregiver.

Another self-care behavior not studied but important to elder caregivers would be caregiver management of caregiver chronic illness, such as hypertension, diabetes mellitus or glaucoma. The CNS could assist the caregiver in dealing with any caregiver's chronic illness. Since caregivers make their own decisions about self-care behaviors, the CNS would need to educate caregivers in why the prescribed treatment regime needs to be followed. The CNS could then instruct the caregiver in planning caregiver duties around any limitations the caregiver may have. For example, if the caregiver has arthritis, the caregiver probably experiences less pain and joint stiffness at the beginning of the day. The CNS could teach the caregiver to arrange caregiving duties so that the more physical duties, such as bathing and grooming, be performed at the beginning of the day. The CNS could also educate the caregiver about medications the caregiver may be taking for chronic illness. The caregiver would need to know the route of administration, times to be administered, what to do if a dose is missed and any side effects the caregiver should be monitoring for. In order to assure that a busy caregiver takes medications as prescribed, the CNS could teach the caregiver to construct a calendar with times on it to be checked off by the caregiver when a medication was taken.

In summary, the CNS can develop multiple strategies for assisting the caregiver with promoting their own self-care behaviors. The strategies include arranging for services for the caregiver, teaching the caregiver to develop a respite network, instructing the caregiver in time management and meditation and teaching the caregiver how to continue their caregiving duties while managing their own chronic illnesses.

Direction in Education for CNS

To understand caregiving, the CNS must be educated in nursing theory in order to practice at an advanced level. The CNS's advanced education can also be used in hypothesis testing. The CNS must have a sufficient understanding of self-care on which to base her or his practice. The CNS needs to understand existing nursing theory in order to refine components of the theory or even develop a new nursing theory. An advanced education in nursing theory will assist the CNS in developing conceptual definitions so that health care providers are defining concepts consistently and are speaking a common language in regards to these concepts. Future Clinical Nurse Specialists will need to know how to develop scales that are reliable. From this study it has been noted that scale development is difficult. The CNS must have a well developed understanding of the self-care behavior concept in order to develop items that can fit together on a scale. Another concern for the CNS of the future is to discover the various self-care behaviors in which elder caregivers engage.

Implications of Research and Future Research

It has been demonstrated that three self-care behavior sub-scales, nutrition, sleep and exercise, could be created from the self-care behaviors instrument. However, there may or may not be some overlap between various self-care behaviors as evidenced in studies conducted by Powers-LaMoe (1988) and Given, Given and King (1982). Therefore, it has not been demonstrated that each of the self-care behavior sub-scales are measuring only the concepts that they reportedly represent. Milsum (1980) and Bausell (1986) note that nutrition, sleep and exercise are important areas of self-care behaviors. An implication for future research would be to determine if it is possible to develop self-care behavior scales that do not overlap and measure only the specific concept of each self-care behavior.

This study examined only three self-care behaviors. A second implication for future research could be what self-care behavior scales are of specific importance to caregivers. Self-care behavior scales that may be important to elderly caregivers could be use of alcohol, tobacco and drugs, taking medications, monitoring disease, follow up visits, cancer screening, dental care and dealing with grief and death. According to Breslow and Somers (1972), these self-care behaviors are important to the elderly.

A third implication for future research would be to examine self-care behaviors to determine which self-care behaviors caregivers performed before they became caregivers. The researcher would then need to determine if caregiver self-care behaviors were changing since the caregiver began caregiving or if caregiver self-care behaviors were changing due to age or disease. A researcher would also want to determine how caregiver self-care behaviors change over time.

Archbold (1982a), Baines (1984) and Bohm and Rodin (1985) note the possible relationship between caregiver involvement and self-care behaviors. A negative pattern between involvement and self-care behaviors was noted. A negative relationship between involvement and exercise, and involvement and sleep was demonstrated. An implication for future research would be to identify which self-care behaviors are significantly affected by involvement such as managing caregiver chronic illness or self-detection of cancer. A researcher would also want to determine how a relationship between involvement and self-care behaviors is affected by changes in caregiver involvement, such as the death of the debilitated family member or institutionalization of the debilitated family member. Besides examining which self-care behaviors are affected by involvement, the researcher may wish to discover if there are variables that may modify a possible relationship between self-care behaviors and involvement. A possible area to explore could be the caregiver's lack of skills needed for involvement, which may create stress for the caregiver.

Bohm and Rodin (1985) suggest time spent caregiving as a modifying variable having a possible effect on involvement and self-care behaviors. Stone, et al. (1987) note that 31% of caregivers were employed. The variable of working outside the home may also have an impact on involvement and self-care behaviors. Archbold (1982 a and b) indicates that caregiving can be a financial drain, which could also have an impact on the relationship between involvement and self-care behaviors. Proposed modifying variables for further investigation are caregiver finances, employment status of the caregiver, relative health of the caregiver and patient, caregiver gender, family relationship of the caregiver to the patient, duration of caregiving by the caregiver, how changes in involvement alter self-care and caregiver age. Each of these variables either by themselves or in combination could be examined to determine what effect they have on caregiver self-care behaviors and involvement.

As previously noted, caregivers perceived health was rated as good to excellent. However, it has been noted that for at least sleep and exercise, involvement had a negative effect. This would seem to indicate that caregivers are not caring for themselves very well. A possible explanation for this discrepancy could be that while caregivers see themselves as fairly healthy individuals, they may not be performing specific self-care behaviors. A proposed method to determine a truer picture of the caregiver's health would be to ask caregivers how many times in a month they were ill. It could be reasoned that a caregiver who is never ill or is ill a few times per month is healthier than a caregiver who is ill numerous times in month.

To determine which self-care behaviors are significant to the caregiver, a study could be proposed in which the caregivers inform the CNS of which self-care behaviors are of importance to them. The research question could be "what self-care behaviors are important to a group of family caregivers?" The CNS could ask a representative sample of caregivers to list the self-care behaviors in which they engage. The CNS would then have the caregivers list five specific activities in which the caregivers engage to meet a specific self-care behavior. The CNS would compile a master list of all listed activities and construct a self-care behavior instrument. With this self-care behavior instrument, the CNS has an idea of the self-care behaviors caregivers are performing. Items for the instrument would be placed on scales and appropriate psychometric analysis conducted. If the analysis had sufficiently high results, then the CNS would have developed reliable self-care behavior scales as well as determined what self-care behaviors are important to the caregiver. Areas of self-care that could be included in new self-care behavior scales include sexual behavior of the caregiver, control and monitoring of chronic illness of the caregiver, self-examination to detect cancer, response to grief/loss, recreation, and compliance with taking medications.

The CNS could develop intervention studies using a pretest-postest design. The CNS could administer studies using a pretest to determine the knowledge a group of caregivers possesses about self-care behavior, for example cancer detection. The CNS would then provide an educational intervention such as the seven warning signs of cancer, testing stool for occult blood, self breast examination and self testicular examination. The scores from the pretest and postest would be analyzed to determine if the postest scores were significantly greater than the pretest scores. If the postest scores are significantly greater than the pretest scores, then this would indicate that the intervention was effective at one point in time. Other intervention studies could be developed to examine the effectiveness of teaching nutrition, stress managment, dealing with grief/loss and self-management of chronic illness.

Summary

To summarize, three self-care behavior sub-scales were created. The study indicated a negative relationship between the level of caregiving involvement and self-care behaviors of the caregiver (exercise and sleep). Reliability of the sub-scales could be increased by adding more items to the sub-scales. The proposed study model could be further refined to clarify self-care concepts.

The Clinical Nurse Specialist can act as a supporter for the caregiver in assisting the caregiver in overcoming self-care deficits. An implication for future research would be to examine how self-care behaviors are affected as involvement changes. Another implication is to determine what self-care behaviors are affected by involvement. A third implication for future research is to determine which self-care behaviors are important to caregivers and then develop scales to measure those self-care behaviors.

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APPENDIX A

UCRIHS Letter of Approval

MICHIGAN STATE UNIVERSITY UCRIHS Letter of Approval

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

EAST LANSING • MICHIGAN • 48824-1111

May 2, 1989

IRB# 89-212

James Mead
Rm. A217 Life Sciences

Dear Mr. Mead:

Re: "THE RELATIONSHIP OF CAREGIVER INVOLVEMENT AND SELECTED CAREGIVER SELF-CARE BEHAVIORS IRB# 89-212"

The above project is exempt from full UCRIHS review. I have reviewed the proposed research protocol and find that the rights and welfare of human subjects appear to be protected. 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 May 2, 1990.

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

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

Sincerely,

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

JKH/sar

cc: B. Given

APPENDIX B

Consent Form From Original Study

CONSENT FORM

The study in which we are asking you to participate is designed to learn more about the ways in which caring for an older family member affects the individual providing the care. Over the next year, participants, both patients and caregivers, will be interviewed by a member of the research staff three times (at intake, six months, and one year). Each interview will take approximately 1 1/2 hours to complete. In addition, patients and caregivers will be asked to keep a diary of all to participate, please sign the following statement.

1. I have freely consented to take part in a study of patients and their caregivers conducted by the College of Nursing 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 home health care agency or private physician 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 responses may add to the understanding of health care professionals of the experience of being responsible for an older family member.

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

Signed ______________________________ Date __________________________
(signature of patient)

6/20/85

APPENDIX C

Self-care Practices From Original Study

SELF-CARE PRACTICES

Each person has developed life-long habits which may or may not contribute to good health. Health care experts have identified several life-long behaviors which have a direct influence on our personal well-being. We are interested in your current health behaviors. Please answer all statements as honestly as you can. Do not spend too much time on any one question. Please answer all questions by CHECKING the answer that best describes your involvement in each behavior or health practice at this time.

"REGULARLY" means once a week or more.
"OCCASIONALLY" means less than once a week.

	RARELY DO THIS	DO THIS OCCASIONALLY	DO THIS REGULARLY
1. I do vigorous exercise for 15-30 minutes (swimming, jogging, brisk walking, biking).			
2. I eat a variety foods including fresh fruit, raw vegetables, and whole grain breads or cereals.			
3. I eat breakfast.			
4. I drink three or more cups of caffeinated beverages (coffees, teas, or colas).			
5. I take drugs I buy without a prescription.			
6. I get between six and eight hours sleep.			
7. I have uninterrupted sleep.			
8. I fall asleep easily at night without medication.			
9. I drink six to eight glasses of water each day.			
10. I take laxatives.			
11. I take some time for myself.			
12. In the course of your normal day, do you walk at least one continuous mile?			
13. I maintain my weight at either five pounds under or 15 pounds over your ideal weight.			
14. I limit the amount of animal fat, eggs, butter and cream that I eat.			
15. I limit the amount of refined sugar, pastries and sweets that I eat.			
16. I limit the amount of salt I eat and add to foods.			
17. I know the purpose of each of the prescribed medications I take/don't take.			

18. Do you smoke? ___ YES (1) ___ NO (2) ⟶(Go to Question #20)

19. If YES, I smoke: ___ Pipe/Cigar only (1)
___ Less than one pack of cigarettes per day (2)
___ One pack of cigarettes or more per day (3)

20. Have you had your blood pressure checked in the last year?

___ YES (1) ___ NO (2)

21. What other health behaviors do you engage in to maintain and/or promote your health that have not been listed above? Please write in below.

___________________________ ___________________________
___________________________ ___________________________

Please answer all questions by checking the answer that best describes <u>your</u> involvement in each behavior <u>at this time</u>.

"REGULARLY" means once a week or <u>more</u>.
"OCCASIONALLY" means <u>less</u> than once a week.

	RARELY DO THIS	DO THIS OCCASIONALLY	DO THIS REGULARLY
22. Work in garden or yard.			
23. Attend theaters, lectures, concerts.			
24. Attend clubs or lodge meetings.			
25. Attend support group meetings.			
26. Sew, crochet, or knit.			
27. Play cards or other table games.			
28. Listen to TV or radio.			
29. Participate in community activities or church work.			
30. Play golf, other sports, such as tennis or swimming.			
31. Shop.			
32. Read.			
33. Work on some hobby (describe ______________ ______________________________)			
34. Other (describe ______________ ______________________________)			

APPENDIX D

Cornwell Involvement From Original Study

CORNWELL INVOLVEMENT INDEX

1. Does your relative need help with eating?

___ YES (1)

___ NO (2) (Go to question 2)

If YES:

1a How frequently does your relative help with eating?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DOESN'T HELP

1b How frequently do you help your relative with eating?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DOESN'T HELP WITH THIS ACTIVITY

1c How frequently do others help your relative with eating?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DON'T HELP WITH THIS ACTIVITY

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

___ YES (1)

___ NO (2) (Go to question 3)

If YES:

2a How frequently does your relative help with dressing and undressing?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DOESN'T HELP

2b How frequently do you help your relative with dressing and undressing?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DOESN'T HELP WITH THIS ACTIVITY

2c How frequently do others help your relative with dressing and undressing?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DON'T HELP WITH THIS ACTIVITY

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

___YES (1)

___ NO (2) (Go to question 4)

If YES:

3a How frequently does your relative help with combing hair or shaving?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DOESN'T HELP

3b How frequently do you help your relative with combing hair or shaving?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DOESN'T HELP WITH THIS ACTIVITY

3c How frequently do others help your relative with combing hair or shaving?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DON'T HELP WITH THIS ACTIVITY

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

___ YES (1)

___ NO (2) (Go to question 5)

If YES:

4a How frequently does your relative help taking a shower or bath?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DOESN'T HELP

4b How frequently do you help your relative with taking a shower or bath?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DOESN'T HELP WITH THIS ACTIVITY

4c How frequently do others help your relative with taking a shower or bath?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DON'T HELP WITH THIS ACTIVITY

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

___ YES (1)

___ NO (2) (Go to question 6)

If YES:

5a How frequently does your relative help using toilet or commode?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DOESN'T HELP

5b How frequently do you help with toileting or commode?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DOESN'T HELP WITH THIS ACTIVITY

5c How frequently do others help with toileting or commode?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DON'T HELP WITH THIS ACTIVITY

INTERVIEWER: Note that item 6, 7 and 8 have a "NOT APPLICABLE" category.

6. Does your relative need help with walking?

___ YES, relative needs help (1)

___ NO, relative doesn't need help (2) (Go to question 7)

___ Not applicable, relative does not walk (3) (Go to question 7)

If YES:

6a How frequently does the patient walk on own?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DOESN'T HELP

6b How frequently do you help relative with walking?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DOESN'T HELP WITH THIS ACTIVITY

6c How frequently do others help relative with walking?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DON'T HELP WITH THIS ACTIVITY

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

___ YES, relative needs help getting around (1)
___ NO, relative does not need help (Go to question 8) (2)
___ Not applicable, relative does not get around the house (3)
(Go to question 8)

If YES:

7a How frequently does the patient get around the house on own?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DOESN'T HELP

7b How frequently do you help with getting around the house?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DOESN'T HELP WITH THIS ACTIVITY

7c How frequently do others help with getting around the house?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DON'T HELP WITH THIS ACTIVITY

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

___ YES, relative needs help (1)
___ NO, relative does not need help (2) (Go to question 9)
___ Not applicable, relative doesn't get out of bed (3)
(Go to question 9)

If YES:

8a How frequently does your relative need help getting in and out of bed?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DOESN'T HELP

8b How frequently do you help your relative get in and out of bed?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DOESN'T HELP WITH THIS ACTIVITY

8c How frequently do others help your relative get in and out of bed?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DON'T HELP WITH THIS ACTIVITY

9. Does your relative need help with shopping?

___ YES (1)

___ NO (2) (Go to question 10)

If YES:

9a How frequently does your relative help with shopping?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DOESN'T HELP

9b How frequently do you help your relative with shopping?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DOESN'T HELP WITH THIS ACTIVITY

9c How frequently do others help with shopping?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DON'T HELP WITH THIS ACTIVITY

10. Does your relative need help with the housework?

___ YES (1)

___ NO (2) (Go to question 11)

If YES:

10a How frequently does your relative help with the housework?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DOESN'T HELP

10b How frequently do you help your relative with the housework?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DOESN'T HELP WITH THIS ACTIVITY

10c How frequently do others help with the housework?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DON'T HELP WITH THIS ACTIVITY

11. Does your relative need help with laundry?

___ YES (1)

___ NO (2) (Go to question 12)

If YES:

11a How frequently does your relative help with laundry?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DOESN'T HELP

11b How frequently do you help your relative with laundry?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DOESN'T HELP WITH THIS ACTIVITY

11c How frequently do others help with laundry?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DON'T HELP WITH THIS ACTIVITY

12. Does your relative need help with cooking?

___ YES (1)

___ NO (2) (Go to question 13)

If YES:

12a How frequently does your relative help with cooking?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DOESN'T HELP

12b How frequently do you help your relative with cooking?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DOESN'T HELP WITH THIS ACTIVITY

12c How frequently do others help with cooking?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DON'T HELP WITH THIS ACTIVITY

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

___ YES (1)

___ NO (2) (Go to question 14)

If YES:

13a How frequently does your relative help with handling his/her own money?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DOESN'T HELP

13b How frequently do you help your relative handle money?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DOESN'T HELP WITH THIS ACTIVITY

13c How frequently do others help your relative handle money?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DON'T HELP WITH THIS ACTIVITY

INTERVIEWER: Note there is now a NOT APPLICABLE category. Check this category if patient doesn't have treatment or does not need activity.

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

___ YES, relative needs help (1)

___ NO, relative does not need help (2) (Go to question 15)

___ Not applicable, relative does not leave the house (3) (Go to question 15)

If YES:

14a How frequently does your relative help arrange their transportation?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DOESN'T HELP

14b How frequently do you help your relative arrange transportation?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DOESN'T HELP WITH THIS ACTIVITY

14c How frequently do others help your relative arrange transportation?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DON'T HELP WITH THIS ACTIVITY

25. Does your relative need help to be cleaned up when incontinent of urine?

___ YES (1)

___ NO, but uses diapers, depends, catheter, pads (2) (Go to 25a)

___ NO, relative cares for self (3) (Go to question 26)

___ Not incontinent (4) (Go to question 26)

If "YES" or "NO, but":

25a How frequently do you help clean patient from incontinence of urine?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DON'T HELP WITH THIS ACTIVITY

25b How frequently do others help clean patient from incontinence of urine?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DON'T HELP WITH THIS ACTIVITY

27. Does your relative need help to be cleaned up when incontinent of stool?

___ YES, needs help (1)

___ No, but uses diapers, depends, pads, etc. (2) (Go to question 27a)

___ NO, relative cares for self (3) (Go to question 28)

___ Not applicable

___ Not incontinent (Go to question 28)

If "YES" or "No, but":

27a How frequently do you help clean patient from incontinence of stool?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DON'T HELP WITH THIS ACTIVITY

27b Do others help clean patient from incontinence of stool?

ONCE A WEEK OR LESS THAN ONCE A WEEK	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY	DON'T HELP WITH THIS ACTIVITY

29. How many hours per day do you provide direct care for your relative (include: time spent supervising patient and caring for activities; exclude: time spent keeping relative company)? (WRITE IN HOURS)

_______ (hours per day)

> INTERVIEWER: If caregiver answers 24 hours per day, probe this with the following: "How many hours of free time do you have in a usual day?"

30. In the past six months (since we last met) have the number of hours per day you provide direct care for your relative increased, decreased or stay the same? (CHECK ONE)

___ Increased (1)

___ Decreased (2)

___ Stayed about the same (3)