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GENDER DIFFERENCES IN FREQUENCY OF ASSISTANCE AND PERCEIVED ELDERLY PATIENTS' LEVEL OF NEED BY SPOUSE PRIMARY CAREGIVERS WITH THE ACTIVITIES OF DAILY LIVING: DRESSING AND BATHING presented by

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A THESIS

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

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#### ABSTRACT

#### GENDER DIFFERENCES IN FREQUENCY OF ASSISTANCE AND PERCEIVED ELDERLY PATIENTS' LEVEL OF NEED BY SPOUSE PRIMARY CAREGIVERS WITH THE ACTIVITIES OF DAILY LIVING: DRESSING AND BATHING

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Teresa Marie-Peyton Tawil

The demographics of caregivers are changing, and research must anticipate these changes to assist the Gerontological Clinical Nurse Specialist (GCNS) in maintaining pertinent and effective interventions in the homecare situation. This study, using secondary data, and the "Interacting Systems" conceptual framework (King, 1981), focuses on the difference between genders to gain understanding of spouse caregiver assistance with the elderly disabled.

It was found that the level of the elderly patient's need for assistance in dressing and bathing was perceived to be lower when the spouse primary caregiver is male than when female. There was no significant difference between genders with the frequency of assistance provided by the spouse primary caregivers. The implication of these findings on the GCNS are the need to look at the caregivers' gender and appreciate any previous roles and stressors that may be impacting the caregivers' perception and adjust interventions accordingly. TO PRESENT AND FUTURE SPOUSE CAREGIVERS AND THEIR HEALTH CARE PROVIDERS

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CHAPTER I

THE PROBLEM

### Introduction

People are living longer as a result of better nutrition, improved sanitation, and medical technological advancement (Botwinick, 1987). With increased longevity comes an increase in the health problems that are associated with aging and consequently an increased utilization and cost of health care resources has occurred (Matteson, & McConnell, 1988; Worcester, 1990; Bishop, & Karon, 1989). To counteract the rising prices of health care services, federally funded and private insurance programs have restricted the length of time an individual has to recover from an illness in the hospital. For elderly with complex health care needs, this shortened hospital stay means a longer recovery time at home and often the need for in-home assistance (Worcester, 1990).

As individuals age, their chances of having some disability or need for assistance increases at the same time their family and/or financial resources may be limited. Although family members comprise 80% of sources of care for the disabled elderly (Day, 1985), this may not always hold true if families are not given additional assistance. Family caregivers of frail older patients, many of whom are

spouses in compromised health themselves, are at risk for becoming overburdened (Silliman, McGarvey, Raymond, & Fretwell, 1990). When a family feels unable to adequately take care of their loved one at home, they may resort to institutionalization for this patient (Shapiro & Tate, 1988; Newman, Struyk, Wright & Rice, 1990). This can be an emotionally devastating move for the patient and the family, as well as be a costly alternative to homecare.

Who are the family caregivers? Historically women, (daughters, daughters in-law and wives) make up the majority of all family careqivers (Brody, 1990). If spouses are available, they are most likely to be the primary caregivers (Horowitz, 1985). This may change however, since men are living to older ages (Botwinick, 1987), and the proportion of men becoming primary family caregivers and specifically spouse primary caregivers will increase. Furthermore women, who make up the mass of family careqivers presently, are increasingly becoming a higher percentage of the work force and will not be as able to adapt their lifestyle to fit in a careqiving schedule (Day, 1985; Brody, 1990). This trend is likely to escalate as the women of the 60's women's movement are growing older and the traditional female personality traits of affection and nurturing are becoming more androgenous, allowing men to take on the caregiving role more readily (Brody, 1990; Kaye & Applegate, 1990).

Many studies have been done on the activities of caregivers to the elderly (Malonebeach & Zarit, 1991) and

specifically spouse primary careqivers (Winslow & O'Brien, 1992; Ross, 1991; Pruchno & Potashnik, 1989; Pruchno & Resch, 1989; Miller, 1987; Fitting, Rabins, Lucas & Eastham 1986; Zarit, Todd & Zarit, 1986). Research comparing male to female caregivers appears to confirm stereotypic conceptions of gender role allocation (Horowitz, 1985; Stone, Cafferata, & Sangl, 1987; Young & Kahana, 1989). Τn her study of sons and daughters as primary caregivers for their parents, Horowitz (1985) found that, with the exception of health care, daughters are more likely than sons to give hands-on personal assistance to their parents, i.e. transportation, household chores, meal preparation, and personal care which includes grooming, dressing and feeding. Similarly, Young and Kahana (1989), Stone, Cafferata, and Sangl (1987), and Barusch and Spaid (1989), found, in their studies of patient-caregiver dyads, that women tended to provide such things as meal, laundry assistance or other household tasks, while men are more likely to help with less intimate tasks such as help with home repair, transportation, legal assistance and financial management (Young & Kahana, 1989).

Stone, Cafferata, and Sangl's (1987) findings were less conclusive at finding gender differences in such tasks as shopping and transportation. In the same token, Horowitz, (1985) found that in more gender-neutral or traditionally male-oriented tasks such as financial management, financial assistance, or dealing with bureaucratic organizations,

sons' involvement did not differ significantly from that of daughters.

Interestingly however, Barusch and Spaid (1989), found in their study of older adult spouse caregivers, that female patients were more disabled than male patients and that consequently, the male caregivers performed more tasks than female caregivers in the following areas; communication, mobility, hygiene, dressing and feeding. It seems important therefore, to study the amount of assistance provided by gender in a systematic way that will not be altered by individual dependency differences.

The demographics of caregivers are changing, and research must anticipate these changes to assist the Clinical Nurse Specialist in maintaining pertinent and effective interventions in the homecare situation. Because of the importance of both men and women as spouse primary caregivers, this study on spouse primary caregiver assistance will focus on the difference between genders to seek an understanding of contemporary spouse primary caregivers of the elderly disabled.

#### Purpose

In order for the Clinical Nurse Specialist to address the needs of spouse primary caregivers of the elderly disabled, research must be done to fully understand the family homecare situation where interventions can be offered. The purpose of this study is to conduct secondary

data analysis to explore gender differences in spouse primary caregivers' frequency of assistance, and perceived elderly patients' level of need with the activities of daily living: Bathing and Dressing.

#### Statement of the Problem

This author intends to address the following question: What are the gender differences in frequency of assistance and perceived elderly patients' level of need by the spouse primary caregivers with the activities of daily living: Dressing and bathing?

#### <u>Hypotheses</u>

I. As perceived by the spouse primary caregiver, the level of the elderly patient's need for assistance in dressing and bathing is perceived to be lower when the spouse primary caregiver is male than when female.

II. Given perceived need for assistance with the activities of daily living: Dressing and bathing, the frequency of assistance provided by the male spouse primary caregiver is lower than that provided by the female spouse primary caregiver.

In the following section are definitions of the concepts that are relevant to this investigation. The concepts related to this study that will be identified and reviewed are: Male and female spouse primary caregivers; frequency of assistance; and perceived level of patients' need for assistance with the activities of daily living: Dressing and bathing. The following are the conceptual definitions to be utilized in this study.

#### Definitions

## Male and Female Spouse Primary Caregivers

According to Given and Given (1990), a primary caregiver is a person who provides the most care for a patient (e.g. spouse, relative, close friend). Caregivers in the literature, unless stated otherwise, are generally considered to be "informal" or are not compensated by financial reimbursement. Caregiving by relatives is currently the major source of help for the disabled elders in the community. Although the primary caregiver is most likely a spouse or someone that lives in the home, disabled persons with many activities of daily living limitations are more likely to also have some paid assistance (Boaz & Muller, 1992). The primary caregiver in this study is identified as a spouse, who has been married to the care recipient for at least five years, who acknowledges that they are primarily responsible for the caregiving role for their elderly spouse.

Some general characteristics of male and female caregivers have emerged from the recent literature. Male caregivers are found to not be the sole providers of care although they consider themselves the primary caregiver

(Mattocks & Slatt, 1992). Male caregivers are also more likely to assist with the less personal Instrumental Activities of Daily Living as opposed to the Activities of Daily Living that require more personal care (Mattocks & Slatt, 1992).

Female caregivers make up the majority of all family caregivers, which is consistent with traditional thought that women are the more nurturing gender (Brody, 1990). Women caregivers also tend to provide more hours of care and report higher levels of burden, mental distress and physical health decline (Young & Kahana 1989).

# Frequency of Assistance-Provided

The patient's number of functional limitations increases the hours or degree of assistance needed from others (Boaz & Muller, 1992; Ahroni, 1990). Assistance provided will be affected by other factors such as other family caregivers or informal support, as well as assistance received from formal health care agencies. Informal caregivers of the frail elderly however, usually provide care alone or with the assistance of other unpaid help. Those caregivers that do use paid services, care for the most severely disabled elderly patients (Noelker & Bass, 1989; Stone, Cafferata & Sangl, 1987).

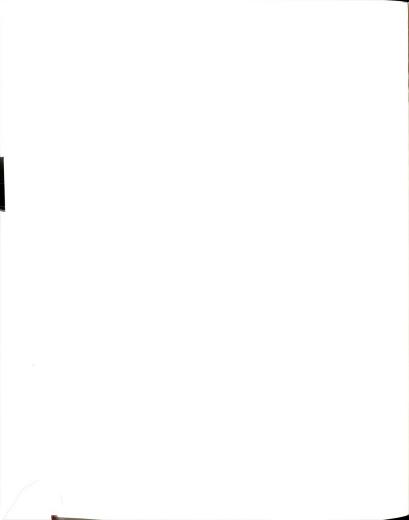
The frequency of assistance can be measured in strictly hours of assistance or in a more detailed scale of intensity such as the breakdown of amounts per day or week. In this

study of spouse primary caregivers of elderly disabled patients, the caregivers state the amount of assistance they have provided to their disabled elderly spouse in an easily estimated frequency using the amounts per day or week.

# Elderly Patient's Level of Need for Assistance with the Activities of Daily Living: Dressing and Bathing

Need for assistance with Activities of Daily Living (ADL's) increase with age, non-white races, poverty and with an increasing percent of the population aged 65 and over. When comparing dependencies of the noninstitutionalized elders by gender, female patients have a greater ADL impairment, but only up to the age of seventy-five years for high poverty communities and eighty years for low and moderate levels of poverty. Male patients have equal to or greater ADL dependencies in the oldest age groups (Elston, Koch, & Weissert 1991).

For this gender comparison of spouse primary caregivers, the patients' need for assistance is based solely on the perception of the spouse caregiver. No measure of etiology of disability will be evaluated. Activities of Daily Living are identified as the following: Dressing, Eating, Bathing, Walking inside the house, Toileting, Transferring in/out of bed. For this study of spouse primary caregivers of elderly disabled patients, the level of assistance needed is conceptualized as the caregiver's stated amount of assistance that the disabled



elderly spouse requires, such as supervision only versus some or total physical help.

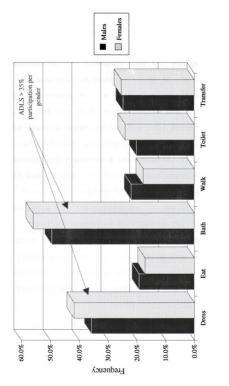
Since the subsample of spouse primary caregivers was relatively small ( $\underline{n} = 322$ ), frequencies were run to identify ADL categories that had high enough "need for assistance" rates to make the analysis statistically significant. The following frequencies were found of spouse primary caregivers that identified their spouse as needing assistance in each ADL (see Figure 1): For **dressing, 39** (35.8%) men and 89 (41.8%) women caregivers; in eating, 21 (19.3%) men and 37 (17.2%) women; bathing, 54 (49.5%) men and 119 (55.9%) women; walking, 24 (22%) men and 38 (17.8%) women; toileting, 22 (20.2%) men and 51 (24.1%) women; and transferring, 27 (24.8%) and 54 (25.4%) women. Since dressing and bathing had the highest percentages, with both being >35% per gender (as well as being highest in the hierarchial structure of the variable - see Chapter III), these were the categories chosen for analysis of this thesis' questions.

#### Overview of Thesis

The following chapters are organized so as to assist the reader to follow and appreciate this systematic investigation. This first chapter is an introduction to the problem; the purpose for the study; the statement of the question; and the conceptual definition of relevant terms.

The conceptual framework of a nursing theorist Imogene







King (1981), has been integrated with this study's concepts in Chapter II. This section also includes a schematic representation of the research question and concepts using Kings' (1981) Integrating Systems conceptual model.

In the third chapter, recent literature is reviewed for studies relevant to the research question and pertinent concepts. An analysis is made in terms of the literature coverage of the concepts. In this section, literature that warrants the need for this investigation was included to enhance the readers appreciation for this authors intention.

The fourth chapter of this thesis, is a description of the methodology and procedures implemented, and a list of limitations and assumptions that are pertinent to the study design and focus. In Chapter V, a detailed presentation of the data analysis and interpretation of results is presented. Finally, presented in Chapter VI, is an interpretation of the findings in comparison with findings in recent literature, the implications of the findings on the Gerontological Clinical Nurse Specialist in primary care, and recommendations for areas of further research.

#### CHAPTER II

#### CONCEPTUAL FRAMEWORK

#### <u>Overview</u>

The intent of this chapter is to describe the nursing conceptual framework utilized in this spouse primary caregiver study of frequency of assistance and perceived level of elderly disabled patients' need with the activities of daily living: dressing and bathing. Through the incorporation of a nursing model, the integration of research findings into advanced nursing practice can be maximized.

### King's Conceptual Framework

Imogene King is a nursing theorist who has formulated a conceptual framework using a systems approach to examine and understand human behavior and ultimately, how peoples' actions relate to nursing care. In this study, King's definition of nursing is adopted as a means to understand the interaction process between the spouse primary caregiver and the elderly disabled patient, as well as the interaction between the Gerontology Clinical Nurse Specialist and the spouse primary caregiver/disabled elderly patient dyad that is discussed in Chapter VI.

Nursing is defined by King as "a process of action,

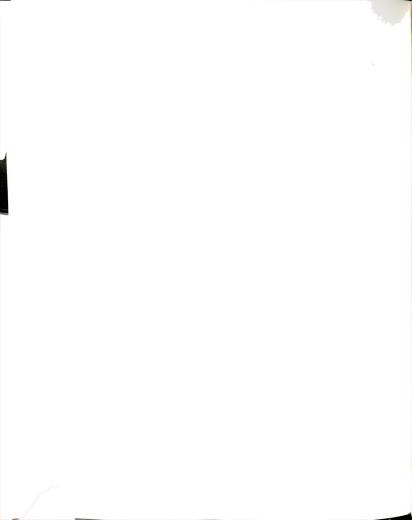
reaction and interaction whereby nurse and client share information about their perceptions" (King, 1981, p. 2). This process of interactions through interpersonal communication is the basis for King's conceptual framework for Nursing. Through communicating goals, problems and concerns in an open verbal exchange, mutual goals can be attained. King (1981) also states that a central focus for nursing must include a way to study human beings as they interact with their environment in order to maintain health. The immediate environment is described by King as the "spacial and temporal reality in which nurse and client establish a relationship to cope with health states and adjust to changes in activities of daily living if the situation demands adjustment" (King, 1981, p.2).

In accordance with King's (1981) definition, nursing is understood in this study as a process of goal oriented, <u>interpersonal communication</u> related to the spouse primary caregivers participation in activities of daily living dressing and bathing, for the primary caregiver's elderly disabled spouse. With this study's findings, the Gerontology Clinical Nurse Specialist can plan appropriate interventions to facilitate the male and female spouse primary caregiver with their prospective needs related to their caregiving situation. Imogene King's focus on the interpersonal expertise of the nursing role and how interpersonal communication leads to goal attainment, is the most influential component of her framework that relates to

this investigation. In Chapter VI of this thesis, the role of the Gerontological Clinical Nurse Specialist is discussed more fully.

King's (1981) conceptual framework is organized around a central focus: human beings. King describes human beings or individuals as "personal systems" (King, 1981, p.10). King's (1981) metaparadigm concept of person includes a dynamic interacting framework in which human beings as open systems relate. Personal systems (individuals), interpersonal systems (groups), and social systems (society) are three forms in which human experience exists, each one impacting the others. Each system has its own set of related subconcepts which reveals how the interactions between and within the systems occur. Figure 2 is Imogene King's visual portrayal of the "dynamic interacting framework" (King, I., 1981, p.11) in which human beings relate. The model has been modified to show where the spouse primary caregiver and elderly patient are represented.

As Figure 2 portrays, each system is open and influences the other two systems. Each system is comprised of human beings perceiving the world as they experience it. People such as the spouse primary caregiver, the elderly disabled patient, (and the Gerontology Clinical Nurse Specialist) were described by King (1981) to be reacting, time oriented and social beings with the ability to perceive, think, feel, choose, set goals, select means to



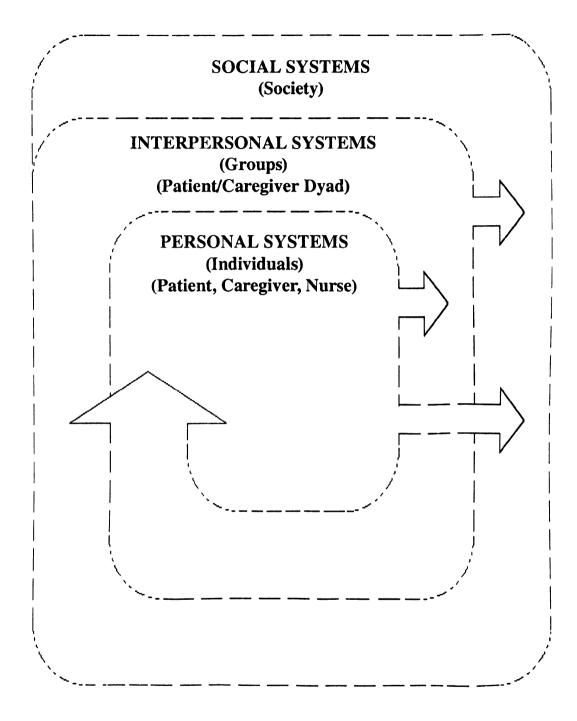
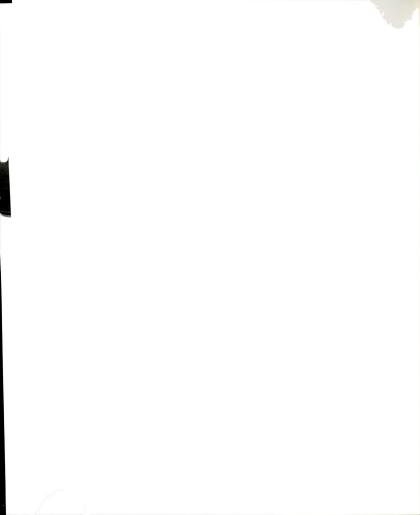


Figure 2: "Dynamic Interacting Systems" from <u>A Theory for Nursing</u> (King, 1981)



achieve goals, and make decisions. These qualities are necessary for spouse primary caregivers to be able to recognize the patients level of needs along with their own interest and ability to become physically involved in caregiving activities.

King (1981) has identified several subconcepts that are essential to the interaction within a dyad or interpersonal systems such as the spouse primary caregiver and the elderly disabled patient, they are: Interaction, communication, transaction, role and stress. These subconcepts identified by King (1981) will be described here first as subconcepts of King's interpersonal systems and secondly as they relate to this thesis on spouse primary caregivers frequency of assistance and the perceived elderly patients' level of need with the activities of daily living: Dressing and bathing.

Interaction is identified as actions occurring between humans and are thus involving perceptions and judgements. Perceptions, judgements and mental actions cannot be directly observed so therefore interactions are evaluated by actions that transpire between individuals. The actions according to King (1981), involve the sequence of first the mental recognition of presenting conditions, secondly the physical initiation and finally the mental action to exert control to reach goal attainment. To make this an interactive process, the two individuals mutually identify goals.

In the case of this study, the spouse primary caregiver

and the elderly disabled patient both perceive and judge the patient's needs for assistance and have opinions on actions to be taken to meet those needs. The part of the primary spouse caregiver/elderly disabled patient dyad interaction that is observable, is the physical exchange that occurs. Additionally, the outcome of the interaction in the form of goal attainment can be observed. Through the interaction process, the spouse primary caregiver mutually identifies goals with the elderly disabled patient regarding the patient's needs for assistance and actions to be taken to meet those needs.

Since the interaction, transaction, and communication processes must be observed for evaluation, this thesis using secondary data from spouse primary caregiver interviews, will not be able to directly study these subconcepts. Recent literature relating to the interpersonal process between disabled patients and their family caregivers will be reviewed in Chapter III. In Chapter VI, the implications of the findings on advance nursing practice will be discussed as to appropriate interventions to assist the interactional process of the spouse primary caregiver/elderly disabled patient dyad.

In order for the interaction process to be successful in reaching goal attainment, adequate <u>communication</u> must occur. King (1981) states that "communication is the vehicle by which human relations are developed and maintained" (p. 79). Communication, either verbal or

nonverbal occurs through the exchange of information, thoughts or opinions between two or more persons. Communication is successful when both parties involved provide a respectful atmosphere and desire understanding. Communication is influenced through the physical environment by possible alterations in the transmission or reception of the information. Communication is also dictated by the person's goals, needs and expectations.

The spouse primary caregiver and the disabled elderly patient dyad situation demonstrates these complexities that can impact the communication process. There may be sociocultural and demographic differences between the spouse primary caregivers and the elderly disabled patients that effect how they relay a message as well as how they receive messages. It is beyond the scope of this thesis to study the communication process between the spouse primary caregiver and the disabled elderly patient yet communication is an essential concept related to the understanding of the process in reaching goal attainment.

Communication is not merely action and reaction, but is a dynamic and reciprocal process that could be termed as <u>transactional</u>. Transaction refers to the actual transfer of values that occurs during an effective interpersonal exchange. Transactions are reciprocal in that it must involve more than one person who is exchanging information or values in an effort to achieve bargaining power, negotiation and social exchange. According to King (1981),

transactions are goal-directed behaviors that are meaningful to the persons interacting. Transactions are valued because the goal is worth achieving; therefore, when transactions are completed, "tension or stress is reduced" (p. 82).

The spouse primary caregiver and the elderly disabled patient interact in the home environment and derive goals by means of transactions related to the completion of activities of daily living. In this thesis example, the spouse primary caregiver and patient each share their ideas and values regarding the patient's ability to do his/her own bathing and dressing as well as the caregiver's ability/interest in providing assistance in order to reach the goal of bathing and dressing to the dyad's satisfaction. Each person involved in these transactions are attributed a <u>role</u> in relation to the derived goals i.e. the spouse primary caregiver and the disabled elderly patient. Transactions then are impacted by role expectations and role performance.

An essential concept in Kings (1981) interpersonal systems model is this concept of roles. The concept of roles is based on the premise that a person "as an individual is influenced by one's identification with other persons" (p. 89). This interactionist concept also incorporates the concept of self which includes the individuals' perceptions, needs and goals. Role socialization then is the individuals' perceptions, needs and goals derived by previous learning from functioning as



an individual in a variety of social and interpersonal systems i.e. family, church, school. The concept of self is impacted by adopted roles such as spouse, parent, man/woman, employee, provider or friend. According to King (1981), the "outcome of role socialization is the presentation of self in acquiring a role and in performing a role ... and requires the development of interpersonal competence" (p.90).

In this study, the spouse primary caregiver identifies him/herself to the telephone interviewer as a primary caregiver of their elderly disabled spouse. The spouse primary caregiver's behaviors are influenced by his/her identification and understanding or socialization of this caregiver role. The spouse primary caregiver's role socialization is influenced by the caregiver's perceptions, needs and goals. The perceptions and needs of the spouse primary caregiver are influenced by previous learning from functioning as a male/female individual in social or interpersonal systems such as their family and society as well as other roles they hold or have held in relation to the disabled elderly patient, such as: Spouse, man/woman, provider, dependent, or friend.

One goal of the spouse primary caregiver is to provide care for the disabled elderly spouse and in order to accomplish this goal, the caregiver must interact with this personal system that the role is defined with (the patient). Additional goals may be derived from other roles the spouse

primary caregiver or patient currently holds. Conforming to the new spouse primary caregiver role may bring tension and <u>stress</u> as it is performed simultaneously with previous roles.

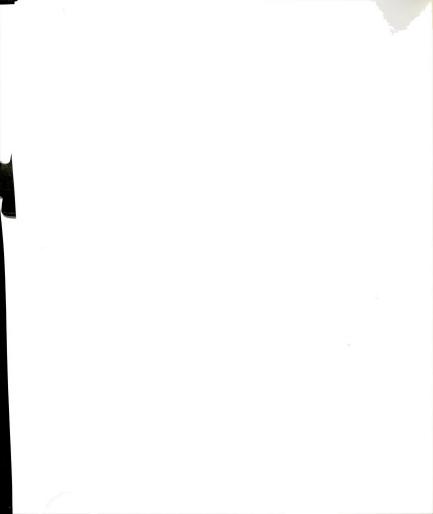
Stress is the final subconcept of Kings (1981) interpersonal systems model that impacts the interactional process of the spouse primary caregiver and elderly disabled patient dyad. King (1981) defines stress as "an energy factor in open systems that is increased and decreased by stressors in man-environment interactions" (p. 98). Stress is considered to be a dynamic state that encompasses physiological, psychological and sociological manifestations. According to King (1981) stress is "individual, personal, and subjective" (p. 98). Individuals may react differently to the same stressors or incident based on their previous experiences and personal coping systems. Stress can be both positive and negative depending on individual reactions and outcomes. The effect of this multidimensional concept is that stress may enhance productivity towards goal achievement as well as simultaneously wear down the achiever.

An important characteristic of stress is that it can be both beneficial and counter-productive as it relates to this study of spouse primary caregivers frequency of assistance and the perceived elderly patients' level of need with the activities of daily living dressing and bathing. A variety of role conflicts and environmental stressors may impact the

spouse caregiver/elderly disabled patient dyad. Although this thesis will not measure the stressors within the caregiver/patient dyad, it is important to keep in mind the importance of stress on the outcome of goal attainment.

The subconcepts King (1981) identifies, interaction, communication, transaction, role and stress, all are essential in the process of "goal attainment" for the spouse primary caregiver/elderly disabled patient didactic interpersonal systems. Two open person systems interacting and making transactions through non-verbal and verbal communication are the precursors to goal-attainment, or achievement of mutual objectives. Perception, including role perception, goals, needs, and values of the spouse primary caregiver and the elderly disabled patient influence this interactional process.

King (1981) has developed a model to represent the interactional or interpersonal relations that occur between two individuals. King's (1981) framework can be utilized to assist the researcher to <u>appreciate</u> the interaction process (though the dyads' relationship will not be studied) that may occur between the disabled elderly patients and their spouse primary caregivers. In this next section, King's (1981) Interacting Systems model will be integrated with the concepts of male and female spouse caregivers, frequency of assistance, levels of assistance with the activities of daily living: Dressing and bathing, to set up the framework for this investigation. King's (1981) interacting systems

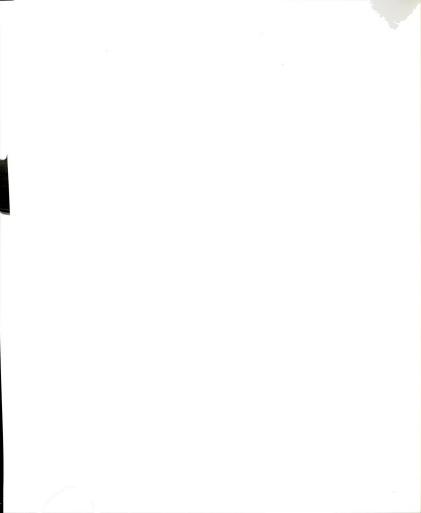


model represents the interpersonal relations that occur between two individuals. King's model (1981), is a living system, the boundaries are semipermeable to allow for an exchange of matter, energy, or information between the system and the environment. This model that visually displays the steps that occur in the process of human interaction, represents the individualized manner that differentiates the male and the female spouse caregiver's assistance with dressing and bathing.

In Figure 3, the male primary spouse caregiver (identified by the solid line), and the female primary spouse caregiver (identified by the two parallel lines), initially perceive the caregiving situation. The process of perception within this interpersonal system is influenced by King's (1981) subconcepts: interaction, communication, transaction, role and stress as discussed earlier. The concept of male/female primary spouse caregivers is portrayed at this step.

The next step in Figure 3, is the male and female primary spouse caregiver's proceeding to judgement of their elderly disabled spouses' level of need with the activities of daily living: Dressing and bathing. The caregivers' judgement is based on the perception in the first step and is reported to the telephone interviewer using previously established categories on the questionnaire (see Appendix F).

The action step in Figure 3, pertains to the male and



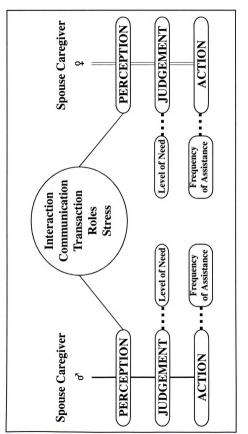


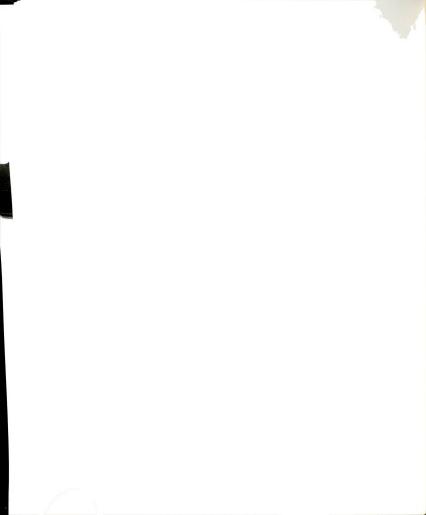
Figure 3: King's (1981) Conceptual Framework Model

female primary spouse caregiver's verbalization of the frequency of assistance they are providing to the elderly disabled spouse with dressing and bathing. This action is also reported by the spouse primary caregiver to the telephone interviewer using previously established categories on the questionnaire (see Appendix F). The three steps: Perception, Judgement, and Action, with independent tracks separating the spouse primary caregivers by gender, depicts the hypotheses that there are gender differences in caregivers' perceived level of need and frequency of assistance.

The elderly disabled patient goes through a similar process of perception, judgement and action, before reaching the final stages of goal attainment as does the spouse primary caregiver. According to King (1981) these final three steps to achieve goal attainment: Reaction, interaction and transaction, pertain to the ongoing interpersonal interactions between the elderly disabled patient and the spouse primary caregiver. These interactions will not be directly studied but will be discussed in Chapter VI.

#### Summary

It is the intent of this investigator, to conduct secondary data analysis to explore gender differences in spouse primary caregivers' frequency of assistance, and perceptions of elderly patients' level of need with the



activities of daily living: Dressing and bathing. The utilization of King's (1981) framework guides the researcher in identifying the factors that influence the spouse primary caregiver's perception of the elderly disabled patient's need and the caregivers frequency of assistance with those needs. Ultimately, through the understanding of spouse primary caregiver perceptions, the Gerontological Clinical Nurse Specialist, the primary spouse caregiver and the patient can proceed with interactions which are productive and lead to interventions that meet the caregiver/patient dyad's needs.

#### CHAPTER III

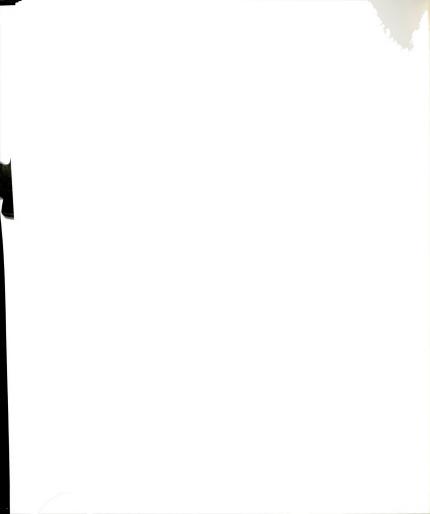
## REVIEW OF RELATED LITERATURE

## **Overview**

In this section, recent literature is reviewed for studies related to the concepts in this thesis on "gender differences in frequency of assistance and perceived elderly patients' level of need by the spouse primary caregivers with the Activities of Daily Living: Dressing and bathing". Analysis is made in terms of the literatures' pertinence and coverage of the concepts of male and female spouse primary caregivers, elderly patient's level of need for assistance with the Activities of Daily Living: Dressing and bathing, and caregiver's frequency of assistance provided.

# Male and Female Spouse Primary Caregivers

This review of literature on male and female spouse caregivers addresses the current knowledge regarding caregiver characteristics in gender, relationship (spouse versus non-spouse), education level, race, and employment. This literature review also describes research that in some way measures or addresses roles, one of the subconcepts of interpersonal systems identified by King (1981) as discussed in Chapter II. Research that relates to roles of male or female caregivers is critiqued in order to establish



pertinence of this investigation. Psychological factors that influence the spouse primary caregiver is mentioned briefly as they impact the interpersonal relationship of the dyad or affect the other subconcepts: Communication, interaction, transaction, role and stress. Though these concepts are not assessed in this thesis, this researcher feels that awareness of their potential impact is important and thus are addressed in this literature review.

## Gender Characteristics

Female caregivers make up the majority of all informal caregivers (Tennstedt, Crawford, & McKinlay 1993) and family caregivers (Malonebeach & Zarit 1991), which is consistent with traditional thought that women are the more nurturing gender (Brody, 1990). Researchers have documented that an unpaid female relative, initiates the primary caregiving role when an elderly person in the family needs help (Lee, Dwyer & Coward, 1993; Boaz & Muller, 1992; Malonebeach & Zarit, 1991; Brody 1990; Sherman, Ward & LaGory 1988; Stone, Cafferata & Sangl 1987; Horowitz 1985). Male caregivers are often found to not be the sole providers of care although they may consider themselves the primary caregiver (Mattocks & Slatt, 1992).

Lee, Dwyer and Coward (1993) looked at correlations in gender of the caregiver in relation to gender of the patient. In their study of adult children from the National Long-Term Survey, Lee et. al. (1993) found that daughters

were three times as likely as sons to provide ADL assistance which is consistent with historical trends. To differentiate if this was due to just the higher number of mothers needing assistance (and therefore the same sex daughter would be the likely caregiver), the researchers looked at the gender of the patient, and found that daughters were also about 40% more likely than sons to assist fathers with ADL tasks in addition to being nearly four times as likely as sons to assist mothers. Although when sons provide ADL's it is most likely to their same sex parent, daughters provided more ADLs overall regardless of gender (Lee, Dwyer & Coward, 1993).

This feminization of caregiving is deeply embedded in our culture. As Brody (1986) points out, "The behavior of adult children tells us that women and men continue to accept the proposition that it is women's role to provide the day-to-day care of the old" (p.198). Traditional Western sex-role socialization has prepared women to assume nurturing roles for their families across the life cycle. But more influential is the reality that women's traditional roles as homemakers have permitted them more flexible free time for elder caregiving than men have had (Horowitz 1985; Sommers 1985).

Brody (1990) suggests however that this flexible availability is disappearing as families change to meet the demands of contemporary life. The trend toward smaller families means that there are and still continue to be fewer



female offspring to provide elder care. Furthermore, both financial imperatives and career goals dictate that more women work outside the home (Himes, 1992). According to Brody (1990), at least half of all working-age women are employed. These women who work understandably have less time to give to caregiving.

## Employment status

In regards to employment status, female caregivers were found to be 10.7% less likely than male caregivers to have full-time jobs (Boaz & Muller, 1992). Boaz and Muller (1992) found in their study on employment characteristics of caregivers from the 1982 National Long Term Care Survey data, that caregiving had no effect on part time employment and only slightly effected full time employment. The researchers explain that full-time workers reduce their hours of informal help by 20 hours a week and thereby caregiving has only a negligible effect on their employment. Based on their findings, Boaz and Muller (1992) in agreement with Brody (1990), go on to propose that as the number of younger women committed to careers increase, their availability as home care providers to the dependent elderly will decrease. This data on employment is most important to younger spouse caregivers and not for primary spouse caregivers of elderly disabled who are likely at or nearing retirement age (Burnside, 1988). Boaz and Muller (1992) do not breakdown their results by age group.

## Education level

Education level was not mentioned as one of the sociodemographic variables critical to the outcomes of family caregiving in Malonebeach and Zarit's (1991) review of current research issues in caregiving to the elderly. Boaz and Muller (1992) however suggest that caregivers with more schooling are more likely to work full-time than parttime and consequently reduce their time contribution to caregiving. These research findings on education level and employment do not specify characteristics by age group or relationship to patient. This again, may limit applicability to the spouse primary caregiver of elderly patients whom is likely of be at or nearing retirement despite the recent increase in part time employment by the 65 and older age group (Burnside, 1988).

#### <u>Race</u>

In regards to the race of the spouse primary caregivers, when race is mentioned, most studies have a convenience sample with predominantly white population (Young & Kahana, 1989; Pruchno & Resch, 1989; Barush & Spaid, 1989). Malonebeach and Zarit (1991) suggest that ethnicity has implications in the outcomes of family caregiving and that more research is needed to compare racial groups. Ethnic differences especially have impact on the older generations that adhere to the more traditional viewpoints on family caregiving (Hess & Markson, 1982).

#### <u>Relationship</u>

In addition to the majority of caregivers being female, Brody (1990) explains that there is a hierarchy in the family as to whom would provide the most care. If a married elderly person becomes disabled, it is most likely that their **spouse** will become the primary provider. This trend has been observed by other researchers (Braithwaite & McGown, 1993; Herth, 1993; Abraham & Berry, 1992; Young & Kahana, 1989; Pruchno & Resch 1989). When men are caregivers they are most likely a spouse and residing with the patient (Tennstedt, Crawford, & McKinlay 1993). Most caregiving spouses are women however, partly do to historical trends as discussed earlier, as well as because women tend to live longer and often marry men older than themselves (Brody, 1990).

#### <u>Role</u>

Caregiving in general has been provided by women in this culture and thus, has been associated with the female sex role (Brody, 1990). Men's traditional sex role socialization has confined them to providing care from the emotional periphery of the family where they engage in instrumental tasks associated with providing and protecting (Kaye & Applegate, 1990a). Research comparing male to female caregivers appears to confirm stereotypic conceptions of gender role allocation (Mattocks & Slatt, 1992; Young & Kahana 1989; Stone, Cafferata & Sangl, 1987). Researchers



suggest that women provide more hands on personal assistance than men do and are better equipped by virtue of having nurtured children to provide expressive emotional support to care recipients. Men in contrast, are more likely to help with less intimate tasks such as home repair, legal assistance and financial management (Mattocks & Slatt, 1992; Young & Kahana 1989; Stone, Cafferata & Sangl, 1987).

Interestingly however, Barusch and Spaid (1989), found in their study of older adult spouse caregivers, that female patients were more disabled than male patients and that consequently, the male caregivers' performed more tasks than female caregivers in the following areas; Communication, mobility, hygiene, dressing and feeding. The researchers discuss that the caregivers activities were not consistent with traditional stereotypes. This emphasizes the importance of looking at the individual dependency differences of the sample when making comparisons between genders since traditional role values are not the only determining factor in the decision making process of providing care.

To explore this perception of gender roles, Kaye and Applegate (1990b) assessed what qualities male caregivers ascribed to themselves and to the performance of specific caregiver tasks. The adjectives to be chosen from, were along the instrumental to affective continuum. These adjectives--"self-sufficient, " "analytical," "competitive" "aggressive," and "forceful" were representative of those

traditionally associated with the male sex role. The other five--"gentle," "compassion," "warm," "loving," and "yielding" - were representative of those traditionally associated with the female sex role (p. 90). The researchers report the men found emotional gratification an important motivating factor and tended to ascribe to themselves many affective traits usually associated with the female role. Some of the men's comments however, suggested that the men had internalized the traditional stereotypic conceptions of gender characteristics; thus, the genderrelated attitudes are more suggestive than conclusive. Also, the subjects were selected because of their participation in support groups. Joining a support group has been associated with a typically feminine coping style (Davies, Priddy & Tinklenberg 1986) and may have biased this sample. Nevertheless, the amount of androgenous responses from the male caregivers, does justify program and service planning to accommodate these less traditional viewpoints.

#### <u>Psychological factors</u>

A final gender characteristic that should be mentioned is that of psychological factors that influence the spouse primary caregiver. Although this researcher does not evaluate emotional factors or their consequence, it is important to note here their potential significance in any findings of gender differences.

Kaye and Applegate (1990a) explain the adaption to the

caregiver role for men caring for disabled elders. "A man who assumes primary caregiving confronts challenges to his earliest and most fundamental self-conceptions" (p. 11). Brought up to be instrumental and to emphasize cognitive over affective aspects of experience, the male caregiver finds in caregiving a series of tasks that require his close emotional involvement. Socialized to provide and protect, he is now asked to nurture, to take on what he has come to think of as women's work.

It has been hypothesized by Young and Kahana (1990), that male caregivers' stoic-intellectual approach keeps them at a greater emotional distance from their tasks and thus, less burdened than women by guilt, depression and other emotional stresses of caregiving. Or as Davies, Priddy and Tinkenberg (1986) suggest, men may learn to mask their feelings more effectively, living out the prevailing stereotype that they should "bear up" and suppress evidence of personal vulnerability.

Men predictably tend not to use support groups in comparison to women (Miller, 1987; Davies, Priddy & Tinklenberg, 1986). Those men that do attend want information and appear more concerned with the concrete issues of care provision than discussing their feelings (Davies, Priddy & Tinklenberg 1986). This is what we would expect from male elder caregivers considering their traditional socialization. Miller (1987) suggests that the male caregivers' interest in tasks and taking charge is an extension of the man's traditional role of authority both at work and at home. Men in her sample of those caring for cognitively impaired spouses, appeared to experience less stress if they were more in control of the caregiving situation.

Researchers have documented that the emotional atmosphere paints a different scenario for the female caregivers. Brody's (1990) study on "Women in the middle" are about those female caregivers who find themselves entangled in a web of competing demands from growing or grown children, a husband, and a needy elder relative (p.4). Apparently however, these women are not cutting down on work time to be caregivers, but rather are trying to add on to it. Undoubtedly these women, trying to do it all, are likely candidates for role overload and probable burnout. The elder female spouse caregiver for example may still continue such caregiver roles as mother, grandmother etc.

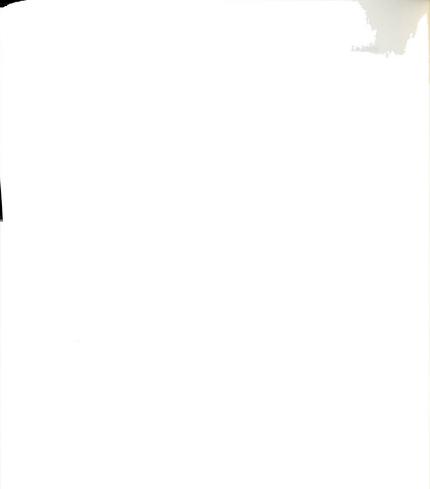
Overall, female caregivers do appear to struggle more than men with balancing their caregiving responsibilities with obligations to others and self (Pratt, Schmall & Wright 1987; Young & Kahana 1989). Noelker and Bass (1989) report, in their study on homecare, that male caregivers were more likely to have assistance with tasks (from kin and formal caregivers) that they did not participate at all in; whereas, female caregivers were given assistance with tasks that they did assist with thus receiving more of a respite type assistance. Female caregivers also reported decreased



social activities because of caregiving. The researchers suggest that this may reflect the female caregivers unwillingness to relinquish any care tasks to service providers whether due to issues of gender or control. This study may be somewhat biased however, as the subjects were selected on the grounds that they were the primary caregiver and that they also provided personal care tasks for their disabled elderly family member. This may have discriminated against those male caregivers that only participate in traditionally masculine tasks such as legal, financial assistance and home repair.

Women caregivers have been found to initiate caregiving because of interpersonal connectedness and caring as opposed to the moral obligatory approach of male caregiver helping (Patterson, 1987). The older rural caregivers in Patterson's (1987) study, also reported different styles of caring. Although both genders report their caregiving style as mainly "doing or providing" care, female family caregivers reported providing a "facilitating of expressive" style of helping more often than male caregivers.

Fitting, Rabins, Lucas and Eastham (1986) found however that male caregivers of their disabled spouse actually reported an improved relationship with their spouse. These researchers suggest that the men, usually retired, are shifting their focus from work to home. These new caregivers may actually enjoy this fresh role because it is a new experience and a means to express their nurturing



de la

feelings, possibly in repayment of that received from their wives. Another possibility that the researchers offer is that the men may have feelings of guilt from the recognition of the sacrifices their wives made throughout their marriage.

In Kaye and Applegate's (1990a) study of male caregivers, the majority of whom were taking care of their spouse, family assistance patterns were uneven. Men were not likely to have more than one, or at the most two, additional family members helping them. Care recipient spouses, sons and daughters were most likely providers of supplementary help. Male caregivers reported using relatively few community services. When community services were utilized they were most likely in-home support services and requests increased as the care recipients' health status deteriorated. Kaye and Applegate (1990a) state that the men in their study did not present themselves as frequent users of formal care and appeared to restrain their usage even as their own health and functional status declined. Whether motivated by male stoicism, a desire to retain control, or gratification derived from sustaining a meaningful relationship, most of these men were going it alone or had minimal help from others. It must be kept in mind however that the male caregivers in Kaye and Applegate's (1990a) study were selected because of their participation in support groups which has been considered a typically feminine coping style.



Most researchers of family caregivers however (Lee, Dwyer & Coward, 1993; Tennstedt, Crawford & McKinlay, 1993; Braithwaite & McGown, 1993; Kaye & Applegate, 1990a; Brody, 1990; Young & Kahana, 1989; Patterson, 1987; Pratt, Schmall & Wright 1987; Fitting, Rabins, Lucas & Eastham, 1986), have not focused in any depth on the communication and transaction processes between the caregiver/patient dyad. Understanding the interpersonal relationship is the key to any speculation on the motivational factors of caregivers. This is an area of future study needed to more fully understand the differences in caregiving between the genders.

Literature discussing caregiver characteristics including gender differences has been discussed. In conclusion, the unique strengths, vulnerabilities and coping styles between the genders are apparent and merit further study on the impact of caregiving.

#### Frequency of Assistance-Provided

The next concept to be reviewed in the literature is that which pertains to the frequency of assistance provided by family caregivers. As was discussed above, some gender differences do exist (Lee, Dwyer & Coward, 1993; Tennstedt, Crawford, & McKinlay 1993; Boaz & Muller, 1992; Mattocks & Slatt, 1992; Malonebeach & Zarit, 1991; Brody 1990; Sherman, Ward & LaGory 1988; Stone, Cafferata & Sangl 1987; Horowitz 1985), and this discussion will review other knowledge and

current measurements of frequency of assistance provided by family caregivers.

In review of literature on family caregivers, it has been found that the patient's number of functional limitations increases the hours or degree of assistance needed from others (Boaz & Muller, 1992; Ahroni, 1990). Assistance provided will be affected by other factors such as other family caregivers or informal support, as well as assistance received from formal health care agencies. Some researchers (Given & Given, 1990; Barusch & Spaid 1989) have measured the number of times specific services or informal support were used for assistance with specific tasks to complete the caregiving picture. Researchers have reported that informal caregivers of the frail elderly usually provide care alone or with the assistance of other unpaid help. Those caregivers that do use paid services, care for the most severely disabled elderly patients (Noelker & Bass, 1989; Stone, Cafferata & Sangl, 1987).

In reviewing the elder caregiving literature, it is noted that the operational definitions of frequency of assistance vary. The frequency of assistance can be measured in hours of assistance (Tennstedt, Crawford & McKinlay, 1993; Winslow & O'Brien 1992; Given & Given, 1990; Stone, Cafferata & Sangl 1987) and/or in a more detailed scale of intensity such as times per day and/or days per week (Given & Given, 1990; Stone, Cafferata & Sangl 1987).

Listing the number of tasks with which the caregiver

assists, was used as the primary measurement of assistance in a study by Lee, Dwyer and Coward (1993), and in addition to other measurements in many other studies (Winslow & O'Brien 1992; Given & Given 1990; Barusch & Spaid 1989; Stone, Cafferata & Sangl 1987). This researcher believes that the validity of the data is limited as to the measurement of care provided if only listing of the tasks is realized. The frequency of assistance can vary so widely as assisting one time only to assisting several times a day and the two should not be considered as equivalent scoring.

Other researchers, (Braithwaite & McGown, 1993; Herth, 1993; Pruchno & Resch, 1989) in their studies evaluating careqiver psychological factors, assessed caregiver involvement very subjectively with a categorical scale on care provided, such as much, some or none. The ambiguous categories provides only subjective data with little reference points for comparability on caregiver involvement since the scales fail to differentiate between frequency of assistance as well as level of care provided. Miller and Montgomery (1990) evaluated the caregivers' subjective appraisal of time with more creativity using the questions "I have to give him/her almost constant attention" or I have to take care of him/her when I don't feel well enough" (p. This in addition to another more operational 79). definition of frequency of assistance provides a wealth of insight into the caregiving situation.

Other researchers (Abraham & Berry 1992; Miller &

Montgomery 1990; Stone, Cafferata & Sangl 1987) have an effective method of measuring caregiver assistance to determine the needs of their caregivers of frail elders. To determine how much a dependent elder impacts the caregivers, the researchers ask the caregivers how much extra time (in hours) beyond their daily routine was spent in giving care. This method will discriminate when such tasks as ADL's or IADL's are provided because the elder is dependent or because the tasks were always done by the caregiver; an important distinction in gender differentiation.

In summary, the literature reveals a variety of operational definitions in frequency of assistance by family caregivers. Researchers that utilize specific measures provide informative as well as dependable information for comparability with other data sets.

# Elderly Patient's Level of Need for Assistance with the

Activities of Daily Living: Dressing and Bathing

This last concept to be discussed will include literature that describes the current knowledge and utilization of tools to measure a patients' level of need for assistance with Activities of Daily Living (ADL's).

Kane & Kane (1981) review several instruments designed to assess patient disability. Many of these tools, such as the Katz Index of ADLs, OARS Multidimensional Functional Assessment, and Barthels' Self Care Index, have been used by researchers to determine elderly patient status (Hughes,



Cummings, Weaver, Manheim, Conrad, & Nash, 1990). The measurement of physical health or patient dependencies, has been divided into hierarchial categories; those that measure the ability to perform basic self-care activities called ADL's and those that measure the ability to perform some of the more complex activities that are associated with independent life called IADL's (Elston, Koch & Weissert, 1991; Kane & Kane, 1981; Leering, 1979).

Elston et. al. (1991) using logistic regression, determined that patients with ADL dependencies also have IADL dependencies. In their study on predictors of functional dependency among the noninstitutionalized population aged 65 and over, the researchers included those patients with ADL dependencies, regardless of their IADL dependencies, into one group called "Personal Care Dependent". The other group of patients in their disability profile of the aged, with only IADL needs, were termed "Mobility or Household Activity Dependent". The researchers reason that ADL's require higher functioning as well as are considered more personal, especially when completed with the assistance of another individual, than IADL's that don't require hands on care. No hierarchial distinctions are made in the Elston et. al study between specific IADLs or ADLs.

Leering (1979) suggests that each ADL demands a higher order of functioning than the preceding activity in ADL list. For example if the patient can bathe, he must be able to eat and dress as well. Some exceptions are noted with



such things as incontinence due to autonomic nerve loss rather than loss of mobility or cognitive functioning. Physical functioning may also be impacted by psychological or social factors such as depression, apathy or anger (Travis & McAuley, 1990; Kane & Kane, 1981).

Researchers have used the ADL categories to identify predictors of functional dependency among the noninstitutionalized population aged 65 and over (Elston, Koch, & Weissert 1991). In their study using the 1984 National Health Interview Survey's Supplement on Aging, Elston et. al (1991) found that ADL dependencies increase with age, non-white races, poverty and with an increasing percent of the population aged 65. When comparing dependencies of the noninstitutionalized elders by gender, the researchers found that female patients have a higher likelihood of ADL dependency, but only up to the age of seventy-five years for high poverty communities and eighty years for low and moderate levels of poverty. Male patients have equal to or greater ADL dependencies in the oldest old age groups. Elston et. al did not count the number of dependencies nor identify specific dependencies in their study but based the "level of need" on generalized categories of ADL's and IADL's.

Most studies measure the level of need for assistance with ADL's by the number of tasks (Lee, Dwyer & Coward, 1993; Winslow & O'Brien, 1992; Abraham & Berry, 1992; Oberst, Thomas, Gass & Ward, 1989; Barusch & Spaid 1989;

Stone, Cafferata & Sangl, (1987). Few studies break this "involvement" down into <u>intensity</u> per task (Given, Stommel, Collins, King, & Given, 1990; Given, King, Collins, & Given, 1988) other than by frequency of assistance (see above concept review). Some studies mesh the two measurements together (frequency and intensity of assistance) by asking overall questions of subjective demand (Braithwaite & McGown, 1993; Herth, 1993; Pruchno & Resch, 1989; Oberst, Thomas, Gass & Ward, 1989).

Cornwell, Given, Given, & King (1987), developed an instrument to measure participation in the ADL's which were identified as: Eating, Dressing, Hair/Shaving, Bathing, Toileting, Ambulation, Getting around (In the home), and In and Out of Bed. The instrument was tested and applied for use with family caregivers of physically impaired elders, Cancer patients, and to caregivers of patients with Alzheimer's disease (Given, Stommel, Collins, King, & Given, 1990; Stommel, Given & Given, 1990; Given, King, Collins & Given, 1988).

The "Functional Involvement Tool" is somewhat unique from the other measurements of level of need for assistance found in the literature in that it specifies frequency, duration, and intensity of the caregivers assistance in the particular activities. Many of the studies reviewed contained a variety of assessment tools looking at different activities that a caregiver could assist with; however, other than the Cornwell et. al. paper and others utilizing

the Functional Involvement Tool, no researchers in recent literature actually differentiate between supervisory assistance and physical assistance levels of care provided for the traditional ADL categories. This may be a very crucial distinction of terms for the elderly whom, as adults, prefer to be treated and thought of as independent persons (Burnside, 1988). Thus, the caregiver may be respecting the patient's wishes by not physically helping, yet are standing by to ensure their safety.

For this investigation of gender differences with spouse caregivers, this author is selecting the Functional Involvement Tool because the items measure the intensity and the frequency that caregivers assist the patient with the various ADLs. However, a limitation of both the studies using the Functional Involvement Tool and the other studies reviewed on caregiver assistance is the lack of comparison between the caregiver's perception and the patient's perception, or any comparison with an assessment from a health care provider. None the less, the Functional Involvement Tool will provide a thorough comparison of male and female spouse caregiver perceived level of need and frequency of assistance and therefore increases the likelihood of obtaining meaningful results.

Literature that describes the current knowledge and utilization of tools to measure a patients' level of need for assistance with Activities of Daily Living have been discussed. The "Functional Involvement Tool", an assessment

tool that will be utilized in this thesis was also introduced and was identified as being the most comprehensive and appropriate tool of measurement for this study.

### Conclusion

In Chapter III, recent literature was reviewed for studies related to the concepts in this thesis on "gender differences in frequency of assistance and perceived elderly patients' level of need by the spouse primary caregivers with the activities of daily living: Dressing and bathing". Analysis was made in terms of the literatures' pertinence and coverage of the concepts of male and female spouse primary caregivers, elderly patient's level of need for assistance with the Activities of Daily Living: Dressing and bathing, and caregiver's frequency of assistance provided. In Chapter IV the statistical methods and data collection procedures are presented.



#### CHAPTER IV

#### METHODS

#### <u>Overview</u>

In this chapter, the statistical methods and the data collection procedures relevant to this study of spouse primary caregivers of elderly disabled are presented. This chapter also includes a brief description of the longitudinal study "Caregiver Responses to Managing Elderly Patients at Home", in which the data of this thesis has originated.

### Design

This thesis is descriptive secondary analysis. As was stated earlier, the data for this thesis were collected via telephone interviews in 1990-92 as part of a longitudinal study "Caregiver Responses to Managing Elderly Patients at Home", (NIA Grant #2 RO1 AG06584-04; Co-principal investigators were Charles W. Given Ph.D., Department of Family Practice, College of Human Medicine, and Barbara A. Given, Ph.D., R.N., F.A.A.N., College of Nursing, both at Michigan State University). The agency granting the four year funding was The National Institute on Aging.

The purpose of descriptive studies such as this thesis, is to observe, describe, and document aspects of a situation

rather than be concerned with the relationships among the variables. This thesis project was designed to identify and describe gender differences in spouse primary caregivers of elderly disabled as reported through the perception of the spouse primary caregiver. More specifically, this study will describe gender differences in reported frequency of assistance and elderly patients' level of need for assistance as perceived by the spouse primary caregivers with the activities of daily living: Dressing and bathing. The **independent variable** is caregiver gender and the **dependent variables** are the spouse primary caregivers' frequency of assistance and the perceived elderly patients' level of need with dressing and bathing.

#### Operational Definitions

In this section, the variables of the hypotheses will be operationalized. Also included in this section will be definitions of eligibility criteria.

# The Elderly Disabled Patient

To be included in the primary longitudinal study, the patient needed to be fifty-five years of age or older and recently discharged from a hospital or rehabilitation center (less than two weeks from the initial screening). For this thesis, additional eligibility criteria were the elderly patients' need for assistance with dressing and bathing (see Appendices B-F).

# The Spouse Primary Caregiver

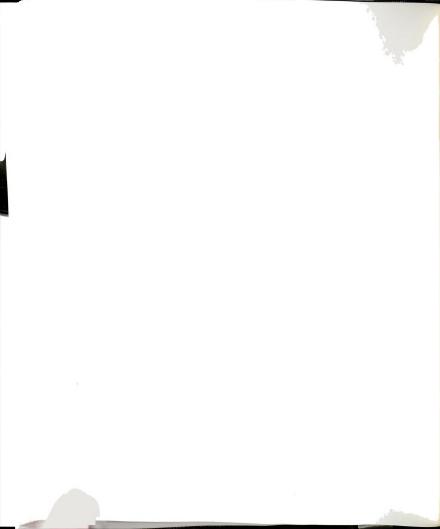
Eligibility criteria for the primary caregivers in the parent study were that the caregiver was not being paid for taking care of the patient, not providing care for any other dependent person during the study and was the person who supervised or provided most of the care for the patient. For inclusion into this thesis study, the caregiver must have been caring for their disabled spouse and was supervising, assisting, or performing their disabled elderly spouse's dressing or bathing (see Appendices B-F).

# The Activities of Daily Living: Dressing and Bathing

The need for assistance with dressing and bathing was self reported by the spouse primary caregiver during the telephone interviews for the primary study (see Appendix F). The following definitions were read to the caregivers during the interviews:

DRESSING - This category includes the entire process of dressing or being clothed, including change from bed clothing into the set of clothing worn during the day, and change to bed clothing at night. This category DOES NOT include management of clothing during toileting. If the elderly disabled patient always wears bed clothing during the day the answer "NEVER DRESSED" would be selected, and the caregiver would not meet the selection criteria.

BATHING - This category includes all activities of



bathing, whether tub or shower or bed bath: entry into tub or shower, wetting, soaping, rinsing, exit, drying body. Bathing DOES NOT include washing of head, drying hair, dressing or undressing.

# Elderly Patient's Level of Need for Assistance with the Activities of Daily Living: Dressing and Bathing

The spouse primary caregivers' self reported perception of the level of assistance needed by the disabled elderly patient with dressing and bathing as collected by telephone interviews for the primary study, was measured using the following scale (see Appendix F):

- 0 = INDEPENDENT -- (does not need help of another person in any part of this activity.)
- 1 = NEEDS SUPERVISION ONLY -- (requires another person present during the activity to instruct or watch for problems, but does not need the physical help of another person.)
- 2 = NEEDS SOME PHYSICAL HELP -- (requires physical help and the presence of another during all or part of this activity.) Elderly disabled patient participates.
- 3 = NEEDS TOTAL PHYSICAL HELP -- (needs another person to carry out this activity.) Elderly disabled



patient does not participate.

# Frequency of Assistance-Provided

The spouse primary caregivers' self reported amount of assistance provided to the disabled elderly patient with the activities of daily living: Dressing and bathing as collected by telephone interviews for the primary study, was measured using the following scale (see Appendix F):

0 = Never

- 1 = Once a week or less
- 2 =Several times a week (2-6)
- 3 = 0nce a day
- 4 = Several times a day

# Research Questions

This author intends to address the following general question: What are the gender differences in frequency of assistance and perceived elderly patients' level of need for assistance by the spouse primary caregivers with the following activities of daily living: Dressing and bathing?

# <u>Hypotheses</u>

I. In instances where spouse primary caregivers report that assistance is required, the <u>level</u> of the elderly patient's need for assistance with dressing and bathing is



perceived to be lower when the spouse primary caregiver is male than when female.

- 1.) Are the reported percentages of elderly patients' level of need for assistance with dressing significantly lower by the male spouse primary caregivers than for the female spouse primary caregivers?
- 2.) Are the reported percentages of elderly patients's level of need for assistance with bathing significantly lower by the male spouse primary caregivers than for the female spouse primary caregivers?
- II. In instances where spouse primary caregivers report that assistance is required with dressing and bathing, the <u>frequency</u> of assistance provided by the male spouse primary caregiver is lower than that provided by the female spouse primary caregiver.
  - 1.) Are the reported percentages of elderly patients's frequency of assistance with dressing significantly lower by the male spouse primary caregivers than for the female spouse primary caregivers?
  - 2.) Are the reported percentages of perceived frequency of assistance with bathing significantly lower by the male spouse primary caregivers than for the female spouse primary caregivers?



### Selection of subjects

This study using secondary data included those subjects from the primary study who were spouse primary caregivers and reported their disabled elderly spouse as needing assistance with dressing or bathing.

# <u>Instrumentation</u>

The telephone interview utilized in this study was composed of close ended questions developed by Given and Given (1990) for their longitudinal study "Caregiver Responses to Managing Elderly Patients at Home". The questions utilized in this thesis are the sociodemographic information on the spouse primary caregiver and the elderly disabled patient (in order to describe the sample and determine the presence of possible modifying variables); also used were four questions of the Functional Involvement Tool developed by Given and Given (1990), based on the Activities of Daily Living (See Appendices D & F). The purpose of the items selected for this thesis were to describe the spouse primary caregivers' perception of their elderly disabled patients level of disability and the caregivers' participation with dressing and bathing.

# <u>Reliability</u>

The reliability of an instrument refers to the stability or consistency when the instrument is administered repeatedly. Reliability is the "degree of consistency with

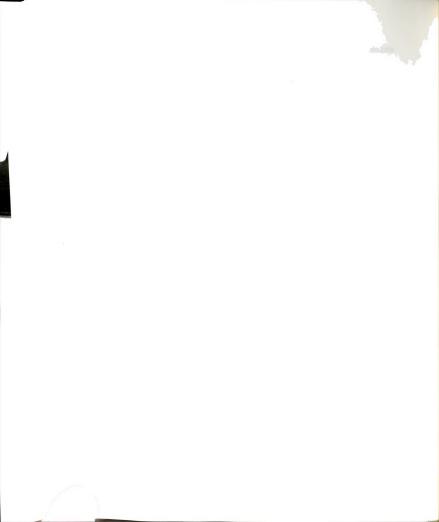


which [an instrument] measures the attribute it is supposed to be measuring" (Polit & Hungler, 1987, p.316). The stability of the Functional Involvement Tool has been established through the repeated use of the tool by the developers in various populations and findings of similar results. The reliability of the Functional Involvement Tool has been determined by Given, Given and Stommel (1990) in their unpublished manuscript "Conceptualization and Measurement of Family Members' Involvement in Caregiving". Given et. al. calculated the coefficient alpha for the Functional Involvement Tool to be .79.

A coefficient alpha of .79 is high enough to indicate internal consistency of the tool in its entirety. However, only two items from the Functional Involvement Tool are used in this thesis; thus, confidence can not be taken with the interpretation of reliability for the Functional Involvement Tool since the instrument was tested with six ADL items and not just dressing and bathing alone. For this thesis using only two items, no scale could be created and no coefficient alpha was calculated.

### <u>Validity</u>

Validity refers to the "degree to which an instrument measures what it is supposed to be measuring" (Polit & Hungler, 1987, p. 323). The content validity has been supported through the literature review in the description of other studies involving similar questions and approaches



supporting this study's conceptual views and study format.

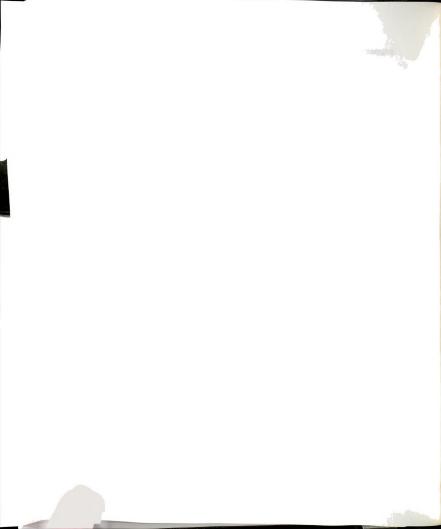
# Data processing and analysis

Demographic information was described in terms of mean, standard deviation, range or percentages (where appropriate) in the following areas: Age, gender, education level, race, and employment.

Statistical analysis consists of crosstabulation with a chi-square statistic computed by summarizing differences between observed and expected frequencies for each cell, enabling this researcher to determine if gender differences were merely chance fluctuations. The significance level of .05 was selected and the degrees of freedom were determined for each table [number of (rows -1) multiplied by the (columns -1)].

In order to further describe gender differences, descriptive statistics (mean and standard deviation) were computed via utilization of the numerical scoring of the independent variables. This will only assist the researcher to determine distribution, not to establish value to the individual levels.

Four tables are included in Chapter V representing the hypotheses and will include data on the number of subjects, observed frequencies and the chi quare statistic. First, the spouse primary caregiver gender was crosstabulated with the four categories of the caregiver's perception of the elderly disabled patients level of need for assistance with



dressing and bathing. Finally, the spouse primary caregiver gender was crosstabulated with the five categories of frequency of assistance with dressing and bathing.

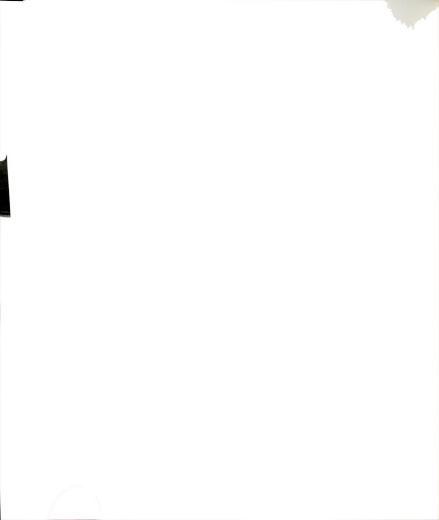
# Procedures for protection of Human Subjects

Protection of the subjects in this study was assured through adherence to the standard criteria provided by the Michigan State University Committee on Research Involving Human Subjects (see approved application: Appendix E).

# Limitations of Study

The limitations of this study included the following:

- (1) Since this study is secondary data analysis, this researcher is limited to the interview format used and the limitations of the original study.
- (2) Using closed ended interview questions may not leave room for expressions of the complexities of human perception and behavior.
- (3) The study results can only be generalized to spouse primary caregivers since there may be differences in the characteristics of the male or female patient whose primary caregiver is their spouse and those whose caregiver is some other individual.
- (4) Due to the sample selection procedure which did not control for extraneous intrinsic variables in the subjects such as sociodemographic factors, factors such as education and social environment can influence the



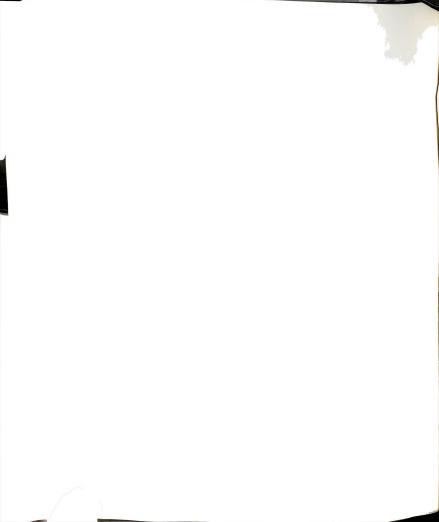
way the spouse primary caregivers interpret the interview questions.

- (5) Due to the initial non-random sample selection process when the dyads were contacted for the initial screening, and the self-selection bias introduced as the subjects decided whether or not to participate in the study, this study's findings are not generalizable to non-volunteers.
- (6) This cross-sectional measurement did not control for the spouse primary caregiver's perception of the patients disability prior to this most recent hospitalization, or any changes in perception that occurred over time with those patients that have chronic disabilities.
- (7) The functional status of the patient is reported only through the viewpoint of the spouse primary caregiver and these views may not be comparable to patients' self assessment or medical assessment of functional status.

## Assumptions of Study

The assumptions of this study include the following:

- (1) The spouse primary caregivers answered the interview questions honestly and openly; if the caregiver did not understand a question, they asked for clarification.
- (2) Interviewers followed their training procedures appropriately to ensure inter-rater reliability.
- (3) The data were recorded and coded without significant

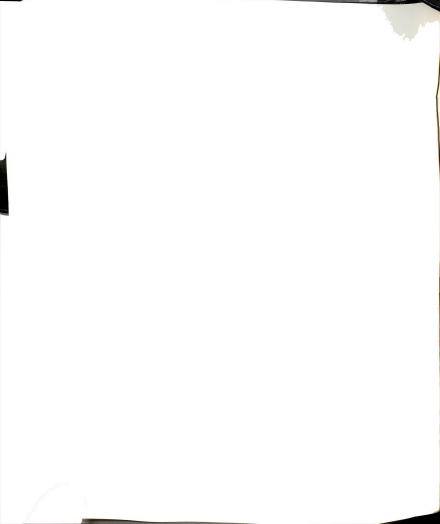


error.

(4) The identified goals were mutually derived between the Gerontological Clinical Nurse Specialist, the spouse primary caregiver and the elderly disabled patient.

### Summary

The methodology and procedures used in this thesis of gender differences in frequency of assistance and perceived elderly patients' level of need by the spouse primary caregivers with the activities of daily living dressing and bathing were presented in Chapter IV. Discussed were the data collection procedures and techniques of the original study as well as the sample selection and data analysis preparations for this thesis utilizing secondary data. In Chapter V, a detailed presentation of the data analysis and interpretation of results is presented.



#### CHAPTER V

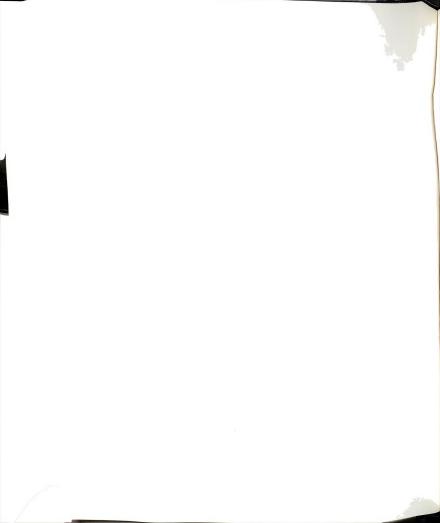
### DATA PRESENTATION AND ANALYSIS

#### <u>Overview</u>

The data presented in this chapter answer the following research question: What are the gender differences in frequency of assistance and perceived elderly patients' level of need for assistance by the spouse primary caregivers with the following activities of daily living: Dressing and bathing? Demographic information are presented to describe the study population (age, gender, education level, race, and employment) in terms of mean, standard deviation, range or percentages (where appropriate).

### Description of the Sample

The sample of 322 spouse primary caregivers used for this study was a subsample of the 628 family caregivers that completed the first wave of telephone interviews for the Given and Given (1990) longitudinal study. Of the 322 spouse primary caregivers, 213 (66.1%) were female and 109 (33.9%) were male (see Figure 4). The majority of the spouse primary caregivers were Caucasian ( $\underline{n} = 293$ ; 91%); twenty-two (6.8%) were Black, four were Hispanic (1.2%) and three were Native American (.9%) (see Figure 5). The ages of the spouse primary caregivers ranged from 44-87 years



a mean age of 67.24 years. The ages of the female use primary caregivers ranged from 44-84 years with a a age of 66.20 years, while the male spouse primary egivers ages ranged from 55-87 with a mean of 69.27. The lents ages ranged from 55-103 years with a mean age of 52 years. The ages of the male patients ranged from 55years with a mean age of 70.10 years, while the female ients ages ranged from 56-88 with a mean of 68.39.

The bulk of the respondents completed high school ( $\underline{n}$  = ; 33.5%). The number of spouse primary caregivers at the er levels of education were as follows: 29 (9%) pleted grade school or less; 78 (24.2%) completed some h school; 59 (18.3%) completed some college; 26 (8.1%) pleted college or technical school; 12 (3.7%) had some duate school; and 10 (3.1%) completed graduate school e Figure 6).

Of the 322 spouse primary caregivers, 98 (30.6%) were bloyed outside the home prior to caregiving, this includes or 31% of the females and 32 or 30% of the males (see ole 1). Sixty-nine of these were employed full time which cludes 42 or 66% of working females and 27 or 84% of cking males. The spouse primary caregiver respondents ported their current employment status to be as follows: employed full time, which includes 12 males and 16 males; 17 employed part time which were all females; 8 If employed, 4 males and 4 females; 186 retired, 89 of ese were males and 97 were females; 6 (all females)

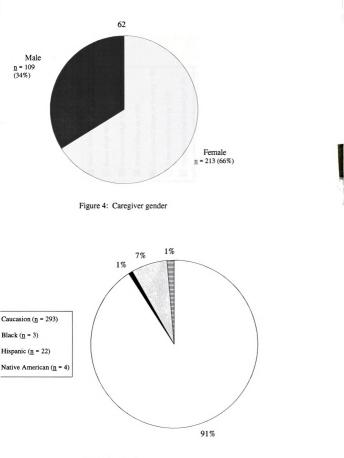
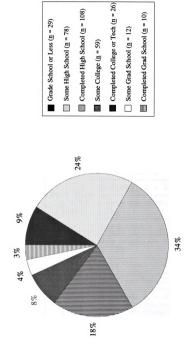
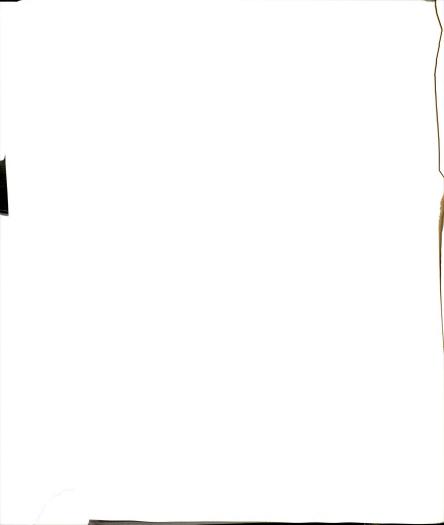


Figure 5: Caregiver race



Education ( $\underline{N} = 322$ )





Male = 108	Employed <u>n</u> = 32 (30%)	Full time <u>n</u> = 27 (84%)	Full time: <u>n</u> = 10 (37%)
			Retired: <u>n</u> = 15 (56%)
			Self employed: $\underline{n} = 1$ (4%)
			Not employed for pay: <u>n</u> = 1 (4%)
		Part time <u>n</u> = 5 (16%)	Full time: <u>n</u> = 1 (20%)
			Self employed: $\underline{n} = 2 (40\%)$
			Retired: <u>n</u> = 2 (40%)
	Not employed: $n = 76 (70\%)$		
Female <u>n</u> = 212	Employed $\underline{n} = 66$ (31%)	Full time <u>n</u> = 42 (64%)	Full time: <u>n</u> = 16 (40%)
			Part time: <u>n</u> = 3 (7%)
			Retired: <u>n</u> = 19 (45%)
			Leave of absence: <u>n</u> = 1 (2%)
			Unemployed: $\underline{n} = 2$ (5%)
			Not employed for pay: <u>n</u> = 1 (2%)
		Part time <u>n</u> = 22 (33%)	Part time: <u>n</u> = 13 (58%)
			Self employed: $\underline{n} = 1$ (5%)
			Retired: <u>n</u> = 2 (9%)
			Leave of absence: <u>n</u> = 3 (14%)
			Unemployed: $\underline{n} = 2$ (9%)
			Not employed for pay: <u>n</u> = 1 (5%)
		Missing cases: $\underline{n} = 2$ (3%)	
	Not employed: <u>n</u> = 146 (69%)		

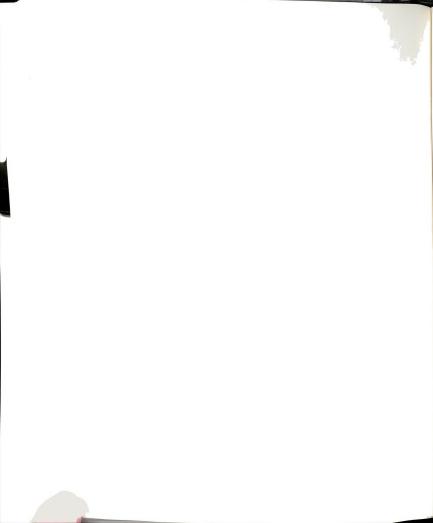
able 1: Caregiver employment status prior to and after caring

Current Status

Prior to caregiving

ender

I



>rted on a leave of absence; 13 (all females) reported ng unemployed; 60 females and 3 males reported being not loyed for pay.

When crossing previous employment with current loyment it was found that of those 69 spouse primary egivers who were previously full time, 26 continued king full time, 3 became part time, one became self bloyed, 34 retired, one took a leave of absence, two came unemployed and two became not employed for pay. Of base 27 spouse primary caregivers who were previously part ne, one began working full time, 13 continued working part me, 3 became self employed, 4 retired, 3 took a leave of sence, 2 became unemployed and one became not employed for y.

# Data presentation for Hypothesis I

1.) Are the reported percentages of elderly patients' level of need for assistance with dressing significantly lower by the male spouse primary caregivers than for the female spouse primary caregivers?

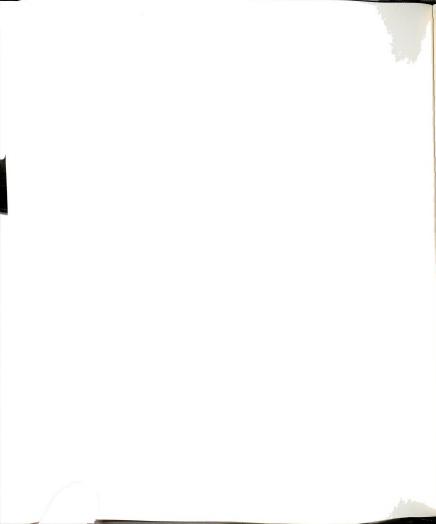
In Table 2 are the findings of the crosstabulation etween the patients' need for assistance with dressing by pouse primary caregiver gender. Those caregivers who report that their spouse is independent with dressing or never dressed ( $\underline{n} = 194$ ) were not eligible for inclusion in this analysis, thus the total number of cases were 128.

Of the male caregivers whom report that their spouse as assistance with dressing, one (2.6%) report their use needs supervision only; 36 (92.3%) need some physical b; and only 2 (5.1%) need total physical help. The over of male spouse primary caregivers reporting for this stion was 39 (36% of the male spouse primary caregivers). Of the female caregivers whom report that their spouse ds assistance with dressing, 11 (12.4%) report their use needs supervision only; 62 (69.7%) need some physical p; and 16 (18%) need total physical help. The number of ale spouse primary caregivers reporting for this question (42% of female spouse primary caregivers).

The Chi-square statistic was 7.78 with two degrees of eedom and was computed to have a significance of .02. For ecceived level of need with dressing by gender, the equency observed in each cell was due to more than chance. Is statistic tells us that gender **may** be the causative ector in the differences between the categories for rceived level of need with dressing.

For spouse primary caregivers identifying their spouses vel of need with dressing where supervision only=1, some lp=2 and total help=3, the mean was 2.03 for men with a andard deviation of .28 and 2.06 for women with a standard viation of .55 (see Table 2).

2.) Are the reported percentages of elderly patients's level of need for assistance with bathing significantly lower by the male spouse primary



caregivers than for the female spouse primary caregivers?

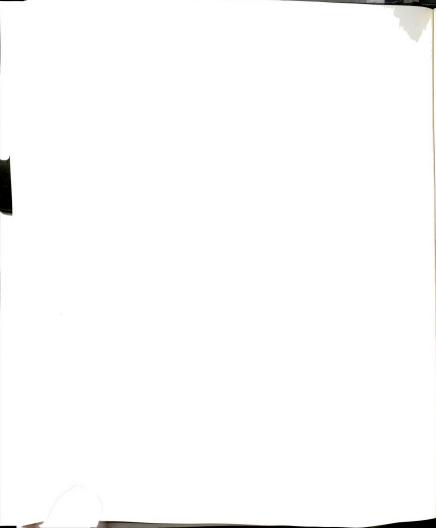
Count Row %	Supervision only	Some Help	Total Help	Total Cases	
males	$\frac{n}{\$} = 1$ $\frac{n}{\$} = 2.6$	<u>n</u> = 36 % = 92.3	<u>n</u> = 2 % = 5.1	$\frac{n}{Mean} = 39$ Mean = 2.03 SD = .28	
females	$\frac{n}{\$} = 11$ $\$ = 12.4$	<u>n</u> = 62 % = 69.7	$\frac{n}{\$} = 16$ $\$ = 18.0$	<u>n</u> = 89 Mean = 2.06 SD = .55	
Chi square = 7.78; Degrees of freedom = 2; Significance = 0.02					

Table 2: DRESSING: Gender by perceived level of need  $(\underline{N} = 128)$ 

In Table 3 are the findings of the crosstabulation etween the patients' need for assistance with bathing by pouse primary caregiver gender. Those caregivers who eport that their spouse is independent with bathing ( $\underline{n} =$ 9) were not eligible for inclusion in this analysis, thus be total number of cases were 173.

Of the male caregivers whom report that their spouse eds assistance with bathing, 5 (9.3%) report their spouse eds supervision only; 41 (75.9%) need some physical help; d 8 (14.8%) need total physical help. The number of male ouse primary caregivers reporting for this question was 54 9.5% of male spouse primary caregivers).

Of the female caregivers whom report that their spouse eds assistance with bathing, 15 (12.6%) report their



spouse needs supervision only; 67 (56.3%) need some physical help; and 37 (31.1%) need total physical help. The number of female spouse primary caregivers for this question was 19 (56% of female spouse primary caregivers).

The Chi-square statistic was 6.43 with two degrees of Ereedom and was computed to have a significance of .04. For berceived level of need with bathing by gender, the Erequency observed in each cell was due to more than chance. This statistic again tells us that gender **may** be the causative factor in the differences between the categories for perceived level of need with bathing.

For spouse primary caregivers identifying their spouses evel of need with bathing where supervision only=1, some help=2 and total help=3, the mean was 2.06 for men with a standard deviation of .49 and 2.18 for women with a standard deviation of .64 (see Table 3).

## Data presentation for Hypothesis II

1.) Are the reported percentages of elderly patients's frequency of assistance with dressing significantly lower by the male spouse primary caregivers than for the female spouse primary caregivers?

In Table 4 are the findings of the crosstabulation between the level of reported caregiver assistance with dressing by caregiver gender. Of the male caregivers who report their spouse needs assistance with dressing, only one



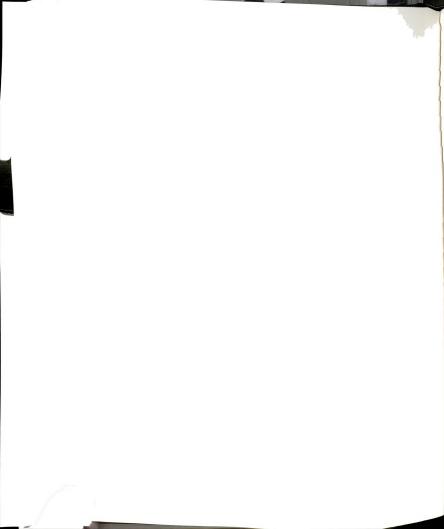
5%%) reports never helping the patient with dressing. ee (7.7%) report helping once a week or less; 7 (17.9%) ort helping several times a week (2-6); 15 (38.5%) report ping once a day; and 13 (33.3%) report helping the ient several times a day with dressing.

Table 3: BATHING: Gender by perceived level of need  $(\underline{N} = 173)$ 

Count Row %	Supervision only			Total Cases	
males	<u>n</u> = 5 % = 9.3	<u>n</u> = 41 % = 75.9	$\frac{n}{8} = 8$ $\frac{14.8}{14.8}$	$\frac{n}{1} = 54$ Mean = 2.06 SD = .49	
females	$\frac{n}{8} = 15$ $\frac{n}{2} = 12.6$	<u>n</u> = 67 % = 56.3	$\frac{n}{8} = 37$ $\frac{n}{8} = 31.1$	$\frac{n}{Mean} = 119$ Mean = 2.18 SD = .64	
Chi square = 6.43; Degrees of freedom = 2; Significance = 0.04					

Of the female caregivers who report their spouse needs esistance with dressing, 4 (4.5%) report never helping the atient with dressing. 6 (6.7%) report helping once a week c less; 7 (7.9%) report helping several times a week (2-6); 0 (33.7%) report helping once a day; and 42 (47.2%) report elping the patient several times a day with dressing.

The Chi-square statistic was 4.20 with 4 degrees of reedom and was computed to have a significance of .38. For requency of assistance with dressing by gender, the requency observed in each cell was not dissimilar than the xpected frequency if this was a random sample. This means



hat gender did not make a difference in the distribution of requency of assistance with dressing.

For caregivers identifying their spouses level of need ith dressing where 0= never, 1= once a week or less, 2= everal times a week, 3= once a day, and 4= several times a ay. The mean was 2.92 for men with a standard deviation of .04 and 3.12 for women with a standard deviation of 1.11 see Table 4).

Table 4: DRESSING: Gender by frequency of assistance  $(\underline{N} = 128)$ 

ount ow %	Never	Once a week or less	Several times a week	Once a day	Several times a day	Total cases
males	<u>n</u> = 1 <b>%</b> = 2.6	$\frac{n}{8} = 3$ $= 7.7$	<u>n</u> = 7 % = 17.9	<u>n</u> = 15 % = 38.5	<u>n</u> = 13 % = 33.3	$\underline{N} = 39$ Mean = 2.92 SD = 1.04
females	$\frac{n}{8} = 4.5$	$\frac{n}{8} = 6$ $\frac{n}{8} = 6.7$	<u>n</u> = 7 % = 7.9	$\frac{n}{\$} = 30$ $\frac{n}{\$} = 33.7$	$\frac{n}{\$} = 42$ $\frac{n}{\$} = 47.2$	$\underline{N} = 89$ Mean = 3.12 SD = 1.11
i square = 4.20; Degrees of freedom = 4; gnificance = 0.38						

2.) Are the reported percentages of perceived frequency of assistance with bathing significantly lower by the male spouse primary caregivers than for the female spouse primary caregivers?

In Table 5 are the findings of the crosstabulation ween the level of reported caregiver assistance with thing by caregiver gender. Of the male caregivers whom port that their spouse needs assistance with bathing, 12



22.2%) report never helping the patient with bathing. 7 13%) report helping once a week or less; 19 (35.2%) report elping several times a week (2-6); 15 (27.8%) report elping once a day; and only one (1.9%) report helping the atient several times a day with bathing.

Of the female caregivers whom report that their spouse eeds assistance with bathing, 12 (10.1%) report never elping the patient with bathing. 18 (15.1%) report helping nce a week or less; 39 (32.8%) report helping several times week (2-6); 41 (34.5%) report helping once a day; and 9 7.6%) report helping the patient several times a day with athing.

The Chi-square statistic was 6.74 with 4 degrees of reedom and was computed to have a significance of .15. For requency of assistance with bathing by gender, the requency observed in each cell was not dissimilar than the pected frequencies if this were a random sample. This ans that gender did not make a difference in the stribution of frequency of assistance with bathing.

For caregivers identifying their spouses level of need th bathing where 0= never, 1= once a week or less, 2= veral times a week, 3= once a day, and 4= several times a y. The mean was 1.74 for men with a standard deviation of 15 and 2.14 for women with a standard deviation of 1.09 se Table 5).

Count Cow %	Never	Once a week or less	Several times a week	Once a day	Several times a day	Total cases
males	<u>n</u> = 12 % = 22.2	<u>n</u> = 7 % = 13	<u>n</u> = 19 % = 35.2	<u>n</u> = 15 % = 27.8	<u>n</u> = 1 % = 1.9	<u>n</u> = 54 Mean = 1.74 SD = 1.15
females	$\frac{n}{8} = 12$ $\frac{n}{8} = 10.1$	<u>n</u> = 18 % = 15.1	$\frac{n}{8} = 39$ $\frac{n}{8} = 32.8$	$\frac{n}{8} = 41$ $\frac{34.5}{2}$	<u>n</u> = 9 % = 7.6	$\underline{n} = 119$ Mean = 2.14 SD = 1.09
Thi square = 6.74; Degrees of freedom = 2; Significance = 0.15						

Table 5: BATHING: Gender by frequency of assistance  $(\underline{N} = 173)$ 

## Summary

In Chapter V, data were presented that described the ubset study population. Crosstabulation with chi-square tatistic were performed for the research questions followed y descriptive statistics (mean and standard deviation) used o provide further information on the data distribution. In hapter VI, the summary, interpretation, and implications of hese findings are presented.

#### CHAPTER VI

# INTERPRETATION, IMPLICATIONS AND RECOMMENDATIONS

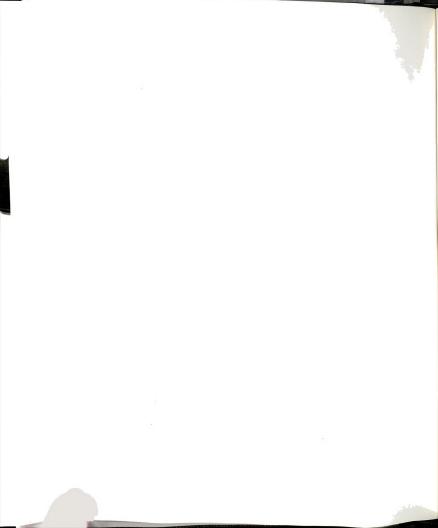
## <u>Overview</u>

This chapter has been organized into three sections. st is an interpretation of the findings with respect to hypotheses, statistical methods and comparison with dings in recent literature. In the second portion of s chapter, the findings in relation to the conceptual mework and the implications for advanced nursing practice discussed. The final section includes recommendations areas of further research.

# Interpretation of the Findings

The demographics of this study population were endent on the sample selection process of the primary gitudinal study. Home care agency personnel determined ject eligibility (see Chapter IV) and if eligible, the mary family caregivers decided if they wanted to ticipate. It should be noted here that this convenience ple and self selection may introduce some sample bias in ms of generalizability to the public. The demographic ormation reported in this thesis pertains to the 322 use primary caregivers of an elderly disabled patient lized for this study on gender comparison.

Of the 322 primary spouse caregivers, the majority of caregivers were female (66.1%) which follows the gender

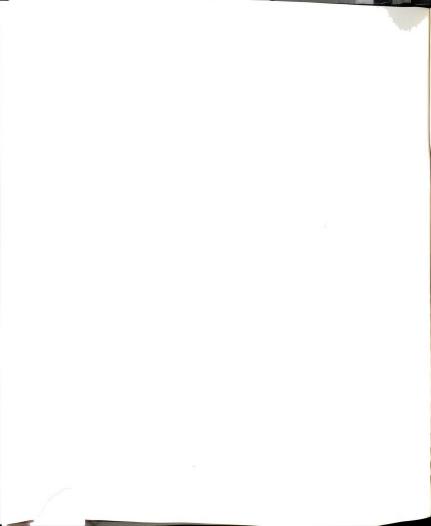


cribution found in the literature (Tennstedt, Crawford, & inlay 1993). Most of the spouse primary caregivers were casian (91%) which was also consistent with other studies ng a convenience sample (Young & Kahana, 1989; Pruchno & ch, 1989; Barush & Spaid, 1989). It has been suggested t ethnicity has implications in the outcomes of family regiving and that more research is needed to compare cial groups (Malonebeach & Zarit, 1991), particularly for der caregivers (Pifer & Bronte, 1986). This racial bias therefore considered a limitation for this study's meralizability.

The education distribution was representative of the mited opportunities for extensive schooling in the 60-70 ar olds' cohort (Pifer & Bronte, 1986). Many of the spouse imary caregivers did not finish high school (33.2%); this including the 9% that only completed grade school or ess.

Female spouse primary caregivers were less likely than ale spouse primary caregivers to have full time jobs prior o caregiving which is consistent with data found in the iterature (Boaz & Muller, 1992). However, both genders ere as likely to be full time at the time of the data ollection thus not introducing a bias towards time for aregiving (see Table 1).

Both the full time and the part time spouse primary aregiver workers reduced in numbers after initiating aregiving. This differs from other researchers who found



Ly a slight impact of caregiving on workers (Boaz & Ller, 1992). This reduction of workers may be due to the creased age and therefore nearing retirement age of the udy sample (the Boaz and Muller (1992) study sample cluded caregivers aged 14 years to 80 years old).

Overall, the effect of caregiving on employment may be e to retirement. The total number of previously employed rior to caregiving) spouse primary caregivers that sported being retired at the time of the data collection as 38 (39%). The number of spouse primary caregivers who eported they took an early retirement because of caregiving as 22 (58% of those recently retired), the other 16 (42%) etired at the time of the interview for other reasons which is likely due to the number of spouse primary caregivers earing retirement age (mean caregiver age is 67.24 yrs).

In summary, after reviewing recent literature, this esearcher has determined that the demographics of the pouse primary caregiver sample for this study were similar o those described in the literature with the exception of he impact of caregiving on employment. Further research is needed to understand the importance of demographics on spouse primary caregivers of the disabled elderly in relationship to perceived level of need and frequency of assistance.



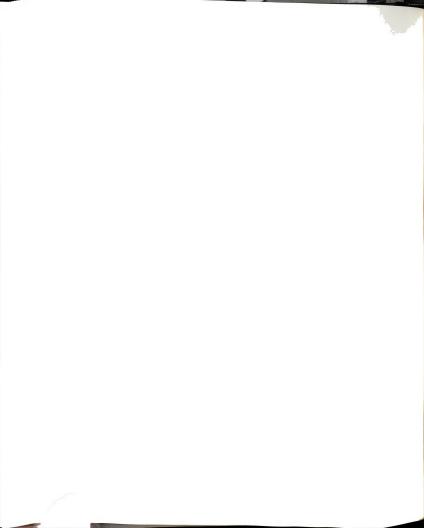
## Interpretation of the Hypotheses

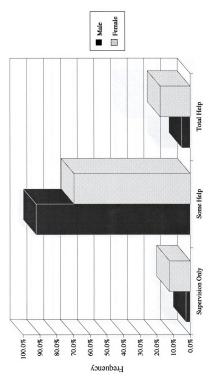
In this subsection, the interpretation of the findings the respect to the hypotheses, statistical methods and mparison with those reported in recent literature will be esented.

# Hypothesis I

In instances where spouse primary caregivers report at assistance is required, the level of the elderly tient's need for assistance with dressing and bathing is preceived to be lower when the spouse primary caregiver is alle than when female. According to the Chi-square catistics in Tables 2 and 3, the null hypothesis was ejected. There are significant (p<.05) gender differences etween the categories for perceived level of need with ressing and bathing. This significance is impacted by the mall degrees of freedom (2) in relationship to the number f participants ( $\underline{n} = 128$  or  $\underline{n} = 173$ ). The Functional nvolvement Tool also included an "Independent" category see Appendix F). If this extra category were included aking the degrees of freedom 3, the gender differences may not have been significant.

The pattern of frequencies for both dressing and bathing may reflect a gender bias in personal care perception. For example, note that female caregivers are more likely to see their disabled spouse as needing supervision with bathing and dressing, than male caregivers







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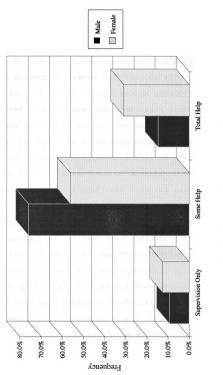
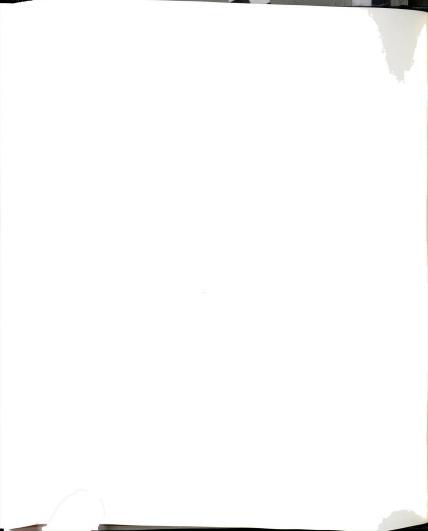


Figure 8: Bathing: Gender by level of need



(see Figures 7 & 8). One could argue that the male and female patients may actually have the same abilities to perform the ADL's but the male caregivers see their wife as independent whereas the female caregivers see their husband as needing supervision. These perceptions would be influenced by previous roles, communication pattern with spouse and current stressors (see Chapter II).

When looking at the overall scores categorically for the perceived level of need for assistance with both dressing and bathing by gender, the male spouse primary careqivers' perceived level of need slightly lower than the female spouse primary caregivers' perceived level of need (see Tables 2 & 3). Regardless of whether or not this difference in means is significant (testing was not done), this researcher is unable to differentiate if the results are based on patient severity of illness or a gender bias in caregiver perception. Others have indicated (through self report by elderly patients) that female patients up to the ages of 75-80 (the mean for female patients in this study is 68 yrs) are more likely to have a higher degree of ADL dependency than male patients of similar ages (the mean for male patients in this study is 70 yrs) (Elston, Koch, & Weissert, 1991). Barusch and Spaid (1989), also found that female patients were more disabled than male patients as reported by older adult spouse caregivers. Thus, the results of this thesis suggest the possibility that the male caregivers perceive their spouses as needing less assistance

with dressing despite the tendency of female patients as being more disabled (according to the literature).

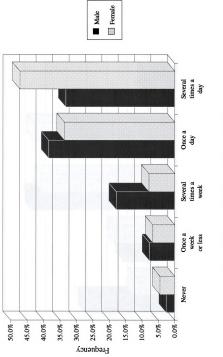
#### Hypothesis II

In instances where caregivers report that assistance is required with bathing and dressing, the frequency of assistance provided by the male spouse primary spouse caregiver is less than that provided by the female spouse primary caregiver.

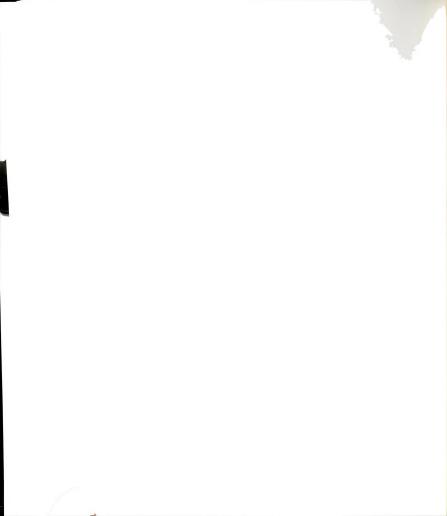
According to the Chi-square statistics for frequency of assistance with dressing and bathing by gender in Tables 4 and 5, the null hypothesis cannot be rejected. The significance of the Chi-square is impacted by the relatively high number of degrees of freedom (4) in relationship to the number of participants ( $\underline{n} = 128$  or  $\underline{n} = 173$ ).

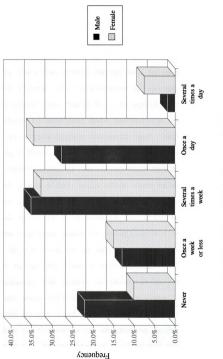
This similarity between the genders in assisting with the traditionally feminine caregiving tasks of bathing and dressing differs from findings in the literature (Mattocks & Slatt, 1992; Young & Kahana, 1989; Stone, Cafferata & Sangl, 1987). However, the pattern of frequencies, as well as the means for both dressing and bathing, may provide some clinically significant data in gender differences. For example with dressing, the female caregivers are more likely to assist several times a day as well as never assist (see Figure 9), in addition to having an overall higher mean score (see Table 4). It could be suggested that compared with male caregivers, female caregivers place more



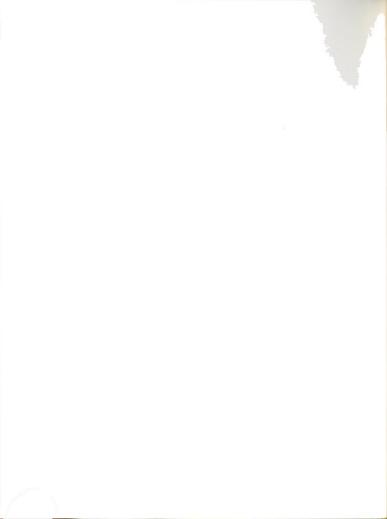












importance or are more habitual at having their husband change clothes more than once a day. In addition, female caregivers may not be able to match the greater physical demand and therefore chose the never assist category (caregiver abilities were not analyzed in this thesis).

With bathing, it is noted that the male caregivers are more likely than the female caregivers to never assist their spouse (see Figure 10), in addition to having an over all lower mean score (see Table 5). It would be consistent with the literature to say that male caregivers are less likely to assist with this highly intimate task (Mattocks & Slatt, 1992; Young & Kahana, 1989; Stone, Cafferata & Sangl, 1987). Female caregivers report assisting with bathing once a day and several times a day, more often than male caregivers (see Figure 10). While this may be consistent with traditional roles to have females assisting more often, it may also be a gender habit in cleanliness since older adults generally do not need to be bathed once a day due to skin changes in aging (Matteson & McConnell, 1988).

In summary, the gender differences in perceived level of need that were anticipated by hypotheses I were demonstrated by the findings in this study. When looking at the variable of frequency of assistance in hypothesis II however, the Chi square statistic does not support a significant difference between the genders. Clinical significance between the genders on the frequency of assistance variable have been discussed and this researcher



suggests that all of these findings increase the wealth of information and understanding of spouse primary caregivers of elderly disabled patients.

#### Implications for Advanced Nursing Practice

This thesis was an effort to determine gender differences in frequency of assistance and perceived elderly patients' level of need by the spouse primary caregivers with the activities of daily living: Dressing and bathing. The purpose of this thesis was to increase the understanding of the family homecare situation to assist the Clinical Nurse Specialist in Gerontology (GCNS) in addressing the needs of the spouse primary caregivers of elderly disabled. In this section, the findings of gender differences in spouse caregivers will be discussed in terms of how these findings affect advanced nursing practice.

As discussed in Chapter II, the focus for nursing is understood in this study as a process of goal oriented, interpersonal communication as defined by the Nursing theorist Dr. Imogene King (1981). For this thesis, King's (1981) conceptual framework provides direction for the GCNS to establish goals and interventions in order to assist spouse caregivers of elderly disabled patients in their caregiving role.

In Figure 11, the perception, judgement and action of the spouse primary, elderly disabled patient and GCNS are presented to illustrate their relationship with the

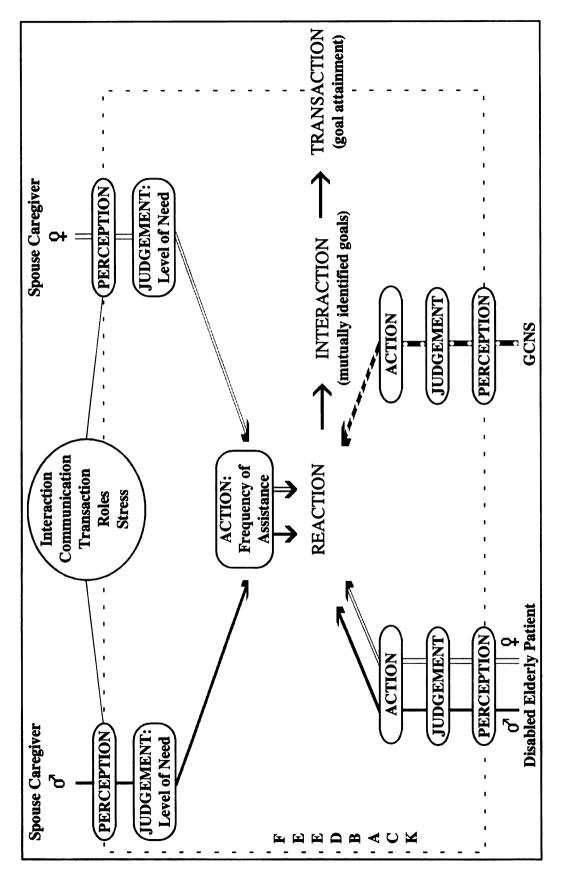


reaction, interaction and transaction that occurs through the interpersonal communication process in accordance with King's (1981) conceptual framework. As is shown in Figure 11, perception, judgement and action all preclude any reaction, interaction, or transaction that occurs between the spouse primary caregiver, the elderly disabled patient and the GCNS. Figure 11 has been changed from Figure 3 to illustrate the findings of significant caregiver gender differences in perceived level of need but not frequency of assistance (as discussed earlier).

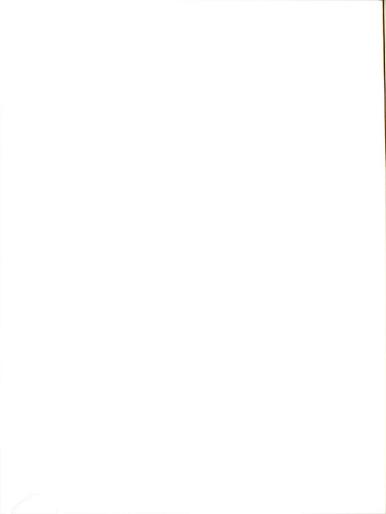
The reaction is the spouse primary caregiver, patient and GCNS response to the caregiving situation; the interaction is that communication between the caregiver/patient dyad and the GCNS identifying mutual goals and interventions to meet the dyads' needs; and the transaction pertains to the achievement of value exchange and the attainment of goals. Though the patient was not studied directly in this thesis, the presence of the patient in this interactional process is anticipated especially since the GCNS would intervene with both the spouse primary caregiver and elderly patient in a therapeutic interaction.

According to King (1981), interpersonal relationships or human interactions are impacted by the perception of each personal system involved. The ultimate focus for the GCNS in the interactional process is facilitation of therapeutic communication of each individuals' perceptions for the attainment of mutually identified goals. In order to









achieve goal attainment or a "transaction", the personal systems (GCNS, and patient) involved in the interaction need to process feedback regarding the perception, judgement and action occurring in the situation. This process which is facilitated by the expertise of the GCNS is ongoing (thus the open dotted "feedback" line in Figure 11) throughout the therapeutic relationship of the personal systems.

The gender differences of perceived level of need and in the various levels of frequency of assistance in addition to the lack of differences on the frequency of assistance variable as a whole that were found in this study, are important for the GCNS to be aware of when facilitating the interactional process within the spouse primary caregiver/elderly disabled patient dyad. The various roles of the nurse in advanced practice will be discussed here in relation to the gender and in utilization of King's (1981) conceptual framework.

The differences (and the lack of differences) in gender will impact the GCNS in his/her role as clinician. In this study, male spouse caregivers were found to perceive the level of the elderly patient's need for assistance in dressing and bathing to be lower than when the spouse primary caregiver is female. These findings do not tell us if the caregivers' perceptions are based on gender bias or severity of patient disability, so it is important that the GCNS is alert (reaction) to the subjectivity of the caregivers' perceptions and utilize standardized assessment

tools as needed if making homecare or clinic assessments. If these perceptual differences are actually due to gender, the GCNS as facilitator must also insure that the goals for the plan of care are defined mutually with each spouse (male and female) so that perceptual discrepancies within the dyad can be negotiated (interaction and eventual transaction).

For example, the female spouse primary caregivers were more likely to report their spouse needs supervision only with bathing and dressing. The male patients may actually feel like they could use some help (instead of just supervision), or on the other hand they may want more privacy, while the female patients may feel they need some supervision to feel safer. The GCNS as facilitator must open the communication lines to insure that the goals for the plan of care are met to the satisfaction of each spouse (male and female). The GCNS using clinical expertise may also recognize some needs not being met or have some safety concerns regarding perceived level of need.

Gender differences were not found to be statistically significant in spouse primary caregivers' frequency of assistance, though there were varying frequencies between the genders when looking at the categories individually. All the findings can offer some clinical significance and impact GCNS interventions directed at assisting the spouse primary caregiver/elderly patient dyad.

For example with bathing, it is noted that the male caregivers are more likely than the female caregivers to



never assist their spouse (see Figure 10). The GCNS could explore with the male spouse primary caregiver to determine if this lack of assistance is do to personal preference or to an actual knowledge deficit in assisting with bathing. The male caregiver may only need some prompting and coaching to assist with this intimate activity but it is also important that the GCNS honors the caregivers' personal and cultural convictions (Kanfer & Goldstein, 1986).

Female caregivers reported assisting with bathing once a day and several times a day, more often than male caregivers (see Figure 10). The GCNS could ascertain if this frequent bathing is due to a gender habit in cleanliness or if the patient has physical conditions such as incontinence or diaphoresis that prompts the caregiver in assisting with bathing at regular and frequent intervals. The male caregivers may be unaware of times their spouse does need frequent bathing and the female caregivers may be unaware that older adults generally do not need to be bathed as often as once a day due to skin changes in aging (Matteson & McConnell, 1988). Since in general there were no significant differences in gender with frequency of caregiver assistance, the GCNS needs to explore the knowledge base behind the caregivers' frequency of assistance to recognize educational needs regardless of gender.

The GCNS in primary care could work as a case manager and in striving for an understanding of the gender

differences in a caregiving situation, would assess the physical, psychosocial and spiritual status of the dyad (Hamric & Spross, 1989; Kanfer & Goldstein, 1986). The GCNS could collaborate with the caregivers' or patients' primary care physician as appropriate. This assessment would include exploring the past experiences of the caregiver and patient, including any caregiving roles in the past, as well as the personal relationship between the spouse primary caregiver and the elderly patient. These assessments provide a better understanding of the caregiving role for both the caregiver/patient dyad and the GCNS. These thorough assessments also assist the GCNS in applying interventions, including making appropriate referrals for additional homecare assistance.

The GCNS also has an important role as educator when finding gender differences. The GCNS would evaluate the knowledge base of the caregiver and patient on the patients' disease process, disabilities and caregiving tasks. The GCNS would then teach the dyad individualized therapeutic interventions that are necessarily performed by either the caregiver or patient as appropriate. The GCNS could also educate about the historical gender differences in the caregiving role and how that could be affecting the individual dyad (Kaye & Applegate, 1990a; Young & Kahana, 1990; Miller, 1987; Davies, Priddy & Tinklenberg, 1896).

As counselor, the GCNS could provide active listening to support the caregiver and/or patient with any stressors



or frustrations with the caregiving situation (Benner & Wrubel, 1989). The GCNS could provide anticipatory guidance to alleviate such problems as burden or depression which female caregivers are specially prone to (Brody, 1990). Caregivers may need help to learn how to delegate responsibility (if others are available). The GCNS could teach improvement of coping skills including the ability to identify the need for assistance with the caregiving role. The GCNS as case manager would also evaluate the caregiver's needs and coordinate services such as: Respite care, transportation, adult day care, formal home care assistance, or durable medical equipment.

In summary, it is the intent of this investigator, to encourage the nurse to explore the interactional process between the patient and the spouse in order to identify mutual goals. By utilizing King's (1981) framework, the nurse, caregiver (and patient) can each increase their awareness and understanding of the situation. After clarifying perceptions, the GCNS as facilitator, counselor, educator, clinician and case manager can proceed with interactions which are productive and lead to interventions that meet the caregiver/patient dyad's needs.

# Recommendations for areas of further research

In conclusion of this thesis, it has been found that there are several areas of further research on the gender differences in spouse primary caregivers. The initial study

that needs to be done is research that compares perceived level of need for assistance, with assessed level of need for assistance, to complete this picture on gender differences in caregiving for disabled elderly. A comparably simultaneous assessment by the patient and/or caregiver and then by a health care provider is needed. This validation of patient and/or caregiver assessment would be helpful in alleviating the need for frequent lengthy (and costly) assessments by health care providers as well as identify gender differences in perception.

A study could also be done to see if the patients' needs are met over time and if the perceived level of need and frequency of assistance change over time (controlling for patient disabilities). This may identify the learning and coping processes of the caregivers and could also be done in correlation with interventions provided by the GCNS. Additionally, research could be done on the spouse caregivers' ability to provide assistance in relation to both physical abilities as well as knowledge base, since these certainly can be major factors in the outcome of assistance provided.

### Summary

In summary, this study on gender differences in frequency of assistance and perceived elderly patients' level of need by the spouse primary caregivers with the activities of daily living: Dressing and Bathing, adds to



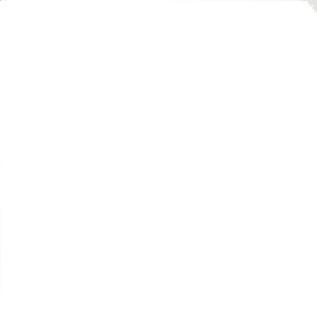
the knowledge base on caregivers and guides the GCNS in developing appropriate interventions to individuals. More research is needed in comparing perceived level of need by caregiver's and/or patient's, with an assessed level of need by a health care provider, for the ultimate goal of matching appropriate health care interventions with the individual caregiving situation.



APPENDICES

APPENDIX A

MSU FAMILY CARE STUDY CONSENT FORM



#### APPENDIX A

## MSU FAMILY CARE 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 elderly family member affects the person providing the care.

Over the next 18 months, 650 caregivers will be interviewed seven (7) times over the telephone by a member of the MSU Family Care Study research staff. Each telephone interview will take approximately 20 to 30 minutes to complete. In addition, you may be asked to complete mailed questionnaires and return them in the self-addressed stamped envelope. The telephone interviews and mailed questionnaires will be completed at your convenience.

If you are willing to participate in this study please read and sign the following statement.

1. I have freely consented to take part in a study of family caregivers conducted by the College of Nursing and the Department of Family Practice, College of Human Medicine, at Michigan State University.

2. The study has been described and explained to me and I understand what my participation will involve, and to remain in the study I must continue to meet the criteria for entry.

3. I understand my participation in this study is voluntary, will involve no cost to me, and that my decision will in no way affect my current or future health care.

4. I understand that I may withdraw from participation at any time without penalty to me by calling 1-800-654-8219.

5. I understand that the results of this study will be treated in strict confidence and, should they be published, my name will remain anonymous. I understand that within these restrictions, results can, upon request, be made available to me.

6. I understand that I will not be placed at any increased risk by participating in this study. Participation does not involve any physical activity. Interviews will be administered by thoroughly trained and closely monitored graduate students in a private and confidential manner.

7. I understand that no immediate benefits will result from my taking part in this study, but am aware that my



responses may add to the understanding of health care professionals and may influence future family care.

8. I understand that I have the right to seek further information about this study, and my rights relating to it, by calling the research office: (517) 355-1851 or toll free, 1-800-654-8219.

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

Signed \_\_\_\_\_

Date\_\_\_\_\_



APPENDIX B

MSU FAMILY CARE STUDY RECRUITMENT FORM

## APPENDIX B

## MSU FAMILY CARE STUDY RECRUITMENT FORM

DISCHARGE	COORDINATOR:		Please complete this form to screen patients and caregivers for entry into the Family Care Study.					
YES	NO	1.	Is the patient 55 years of age or older? If NO, care recipient is NOT eligible. STOP.					
YES	NO	2.	Has the caregiver who plans to care for this patient assisted THIS patient with any of the following activities for three or more consecutive months prior to present hospitalization: eating, bathing, dressing, toileting, or moving around the house?					
			If YES, caregiver is NOT eligible. STOP.					
			If caregiver has assisted with these activities for less than 3 months, they are still eligible.					
		3.	Upon discharge, will the caregiver be supervising, assisting with, or performing any of the following activities for THIS patient?					
YES	NO		dressing					
YES	NO		movement inside the house					
YES	NO		bathing					
YES	NO		toileting					
YES	NO		grocery shopping AND cooking AND transportation					
			If YES to ANY item in #3, caregiver and patient are eligible for the study. PLEASE PROCEED.					
DISCHARGE	COORDINATO	DR:	If patient and caregiver found					



eligible, please present explanation of the study, elicit their willingness to participate in the study, and have and patient sign consent forms.

IF CAREGIVER AND PATIENT CONSENT TO PARTICIPATE, PROCEED BY COMPLETING REMAINDER OF FORM.



APPENDIX C

INTAKE SCREENING



# APPENDIX C

## INTAKE SCREENING

## (Protocol For Telephone Administration Of Screening Instrument)

# Introduction

Hello, my name is \_\_\_\_\_\_. I am a research staff member for a study at Michigan State University Colleges of Nursing and Medicine. We are conducting a study to better understand the experience of being a caregiver for an older person at home. Recently, you expressed a willingness to participate in this study which was described to you by the discharge coordinator at the hospital from which your relative or friend was recently discharged.

Would this be a convenient time for you to answer some brief questions about you and the person for whom you provide care? The purpose of these first questions is to help us describe your caregiving situation and determine your eligibility for the study. This will take about 10 minutes.

> IF PERSON DECLINES AT THIS TIME, TRY TO RESCHEDULE FOR SCREENING. THANK CAREGIVER FOR THEIR TIME.

IF YES, CONTINUE.

Before we begin, I would like to assure you that answering these questions is completely voluntary and that your answers are confidential SCREENING INTERVIEW

Fill in information in questions 1-6 prior (INTERVIEWER: to screening and confirm information and spellings with caregiver at screening.) 1. Name of care recipient:\_\_\_\_\_ Name of caregiver:\_\_\_\_\_ 2. Address of caregiver:\_\_\_\_\_ 3. Telephone number of caregiver: ( ) 4. \_\_\_\_Male \_\_\_\_Female 5. Sex of caregiver: \_\_\_Male \_\_\_Female 6. Sex of patient: month day year 7. Patient Birthdate: 8. Caregiver Birthdate: month day year Primary Caregiver Are you the person who supervises or cares for 9. most of the time? YES (GO TO 10) NO (If NO, ask questions below and STOP screening.) If NO, who is the person who is now supervising or providing the most care for this patient? Name:\_\_\_\_\_ Relationship to patient:\_\_\_\_\_ Do you think this person might be willing to be contacted for participation in this study? YES \_\_\_\_NO If YES, what is this person's telephone number?\_\_\_\_\_



What is the most convenient time to contact them?\_\_\_\_

10. First, I'm going to ask you about your current involvement in different types of assistance for your relative/friend. For each activity I read I'd like to know if you are supervising, assisting, or doing completely for (care recipient) because of physical or other health limitations. Then I will want to know for how long you have been providing assistance at this current level of involvement (i.e. one month or less, one to three months, or three to six months)

INTERVIEWERS: YOU MAY NEED TO REMIND RESPONDENTS OF DATES (e.g. "Now, one month ago would be since \_\_\_\_\_, and three months ago would have been \_\_\_\_\_, and six months would be \_\_\_\_\_)

FOR CURRENT LEVEL OF,HOW LONG AT THISINVOLVEMENT CIRCLE ONE:CURRENT LEVEL:

0 = NOT INVOLVED1 = ONE MONTH OR LESS1 = SUPERVISING2 = ONE TO THREE MONTHS2 = ASSISTING3 = THREE TO SIX MONTHS3 = DOING COMPLETELY4 = MORE THAN SIX MONTHS

	<u>CURRENTLY</u> , AT WHAT LEVEL ARE YOU INVOLVED WITH:				HOW LONG HAVE YOU BEEN INVOLVED WITH THIS ACTIVITY, <u>AT THIS</u> <u>CURRENT LEVEL</u> :				
A. (IADL)									
Cooking (1)	0	1	2	3	1	2	3	4	
Transportation (2)	0	1	2	3	1	2	3	4	
Grocery shopping (3)	0	1	2	3	1	2	3	4	
Other shopping (4)	0	1	2	3	1	2	3	4	
Laundry (5)	0	1	2	3	1	2	3	4	
Money management (6)	0	1	2	3	1	2	3	4	
Housework (7)	0	1	2	3	1	2	3	4	

B. (ADL)								
Bathing (1)	0	1	2	3	1	2	3	4
Dressing (2)	0	1	2	3	1	2	3	4
Toileting (3)	0	1	2	3	1	2	3	4
Moving inside the house/ Walking (4)	0	1	2	3	1	2	3	4
Getting in/out of bed (5)	0	1	2	3	1	2	3	4
Eating (6)	0	1	2	3	1	2	3	4

12. Some people are paid by the Department of Social Services or insurance companies to take care of a relative or friend. Are you being paid for taking care of (\_\_\_\_)?

\_\_\_\_YES (1) \_\_\_\_NO (2)

13. Are you:

\_\_\_\_ a relative to this patient? \_\_\_\_ a non-relative to this patient?

14. Is this your first experience caring for a disabled or dependent relative or friend? (This may include physically or developmentally disabled children/adults.)

YES (1) (GO TO CHECKPOINT) NO (2)

**If NO**, <u>at this time</u> are you caring for more than one disabled person? (Other person may be any age.)

\_\_\_\_YES (1) \_\_\_\_NO (2)

INTERVIEWER: Determine eligibility by CHECKPOINT.

#### 15. CHECKPOINT

a. Is the patient 65 or older?

YES NO

b. Is the caregiver a primary caregiver?

YES NO

c. Is the caregiver supervising or assisting with at least one ADL (Section B in question 10?)

\_\_YES \_\_NO

- d. Has the caregiver reported:
  - Two or more increases in IADL activities (Section A in Q.10)

YES NO

2) One or More increases in ADL Activities (Section B in Q. 10)

YES NO

3) One increase in Equipment and/or Health Care Activities (Section C)

YES NO

FOR ELIGIBILITY THERE MUST BE AT LEAST ONE "YES" in 1, 2, or 3 ABOVE)

- e. Is the caregiver caring for more than one dependent person at this time? \_\_\_YES \_\_\_NO
- f. Is the caregiver a non-relative being paid to care for the patient? \_\_\_\_YES \_\_\_NO

IF ALL CHECKS ARE IN THE BOXES, CAREGIVER QUALIFIES FOR ENTRY INTO THE STUDY. PROCEED.

16. Caregiver is:

\_\_\_\_ Eligible for the study. Not Eligible for the study.

If caregiver is **<u>NOT</u>** eligible:

"Thank you for taking the time to answer these questions. In reviewing the information you just provided for us, your caregiving situation does not qualify for inclusion in this particular study. At this time we will not plan to contact you again. Thank you again for your time and interest."

If <u>IS</u> eligible:

"From reviewing the information that you just provided for us, we would like to include you in our study of caregivers to elderly patients."

17. Would you be willing to participate in our study?

YES (1) NO (2) (GO TO **B**)

A) **If YES**, explain study participation and when intake interview will occur.



Thank you for completing this screening interview and for your willingness to participate in this research study.

In two to three weeks you will receive a questionnaire in the mail. Please complete it at your convenience and return it in the enclosed envelope within a week. You will also be called by an interviewer to complete the intake interview. These materials ask you about your preparation for caregiving, the tasks that you do, and your reactions to caring for your patient.

Again, thank you.

When would be a convenient time to contact you to set up a time for your interview?

B) If NO, would you be willing to let us know what your reasons are for not participating in the study at this time?

REASONS FOR NOT PARTICIPATING

Thank you again for your time. If for any reason you change your mind and decide that you would like to participate feel free to call to arrange another interview. APPENDIX D

SOCIODEMOGRAPHIC INFORMATION

# APPENDIX D

# SOCIODEMOGRAPHIC INFORMATION

In this first set of questions I'd like to ask for some background information about you and your relative/friend.

1. INTERVIEWER: Code sex of caregiver.

	Caregiver is: Male (1) Female (2) Patient is: Male (1) Female (2)
2.	What is your () marital status? (CHECK ONE)
	<pre> Single, never married (1) Married/ Remarried (2) Divorced (3) Widowed (4) Separated (5)</pre>
3.	What is your relationship to the person for whom you provide care? You are his/her: <b>(CHECK ONE)</b>
	<pre>Spouse (1)Parent (2)Daughter (3)Son (4)Daughter-in-law (5)Son-in-law (6)Sister (7)Brother (8)Sister-in-law (9)Brother-in-law (10)Granddaughter (11)Grandson (12)Niece (13)Nephew (14)Niece (13)Nephew (14)Niece (13)Nephew (14)Niece (13)Nephew (14)Nephew (14)Nephew (14)Nephew (14)Nephew (16)Other Relative (18)Other Non-Relative (20)</pre>
4.	What is your race? (CHECK ONE)
	<pre> Caucasian (1) African American (2) Mexican American (3) Native American (4) Oriental/Asian/Pacific Islander (5) Other (Please specify:) (6)</pre>
5.	What is your highest level of education? (CHECK ONE)
	<pre>Completed grade school (1) Completed some high school (2) Completed high school (3)</pre>



Completed some college or technical training (4)
Completed college (5)
Completed some graduate or professional school (6)

- \_\_\_\_ Completed graduate or professional degree (7)
- 6. What is the marital status of <u>(relative)</u>? Are they: (INTERVIEWER: IF CAREGIVER IS SPOUSE, THEN SIMPLY CODE MARRIED)

#### (CHECK ONE)

- \_\_\_\_ Single, never married (1)
- \_\_\_\_ Married/ Remarried
- \_\_\_\_ Divorced (3)
- \_\_\_\_ Widowed (4)
- \_\_\_\_ Separated (5)

## CAREGIVER EMPLOYMENT (Selected Items)

In the next set of questions we would like to know about your employment status and work for pay outside the home.

1. Were you employed outside the home <u>previous</u> to your caregiving responsibility? (CHECK ONE)

\_\_\_\_ YES - Then ASK and CIRCLE ONE: Full-Time Part-Time \_\_\_\_ NO

- 2. What is your <u>current</u> employment status? Are you: INTERVIEWER: PLEASE, CHECK ONE APPROPRIATE CATEGORY
  - \_\_\_\_ Employed Full-Time
  - \_\_\_\_ Employed Part-Time
  - \_\_\_\_ Self Employed
  - \_\_\_\_ Retired
  - \_\_\_\_ Leave of Absence
  - \_\_\_\_ Unemployed (Laid-off; Between Jobs; Disability)
  - \_\_\_\_ Not Employed for Pay Outside the Home (e.g.
  - Homemaker)
  - \_\_\_\_ Quit Work to Care for (Patient's Name)



APPENDIX E

APPLICATION FOR REVIEW OF A PROJECT INVOLVING HUMAN SUBJECTS

#### APPENDIX E

#### APPLICATION FOR REVIEW OF A PROJECT INVOLVING HUMAN SUBJECTS

Responsible faculty: Dr. Barbara A. Given

Address for comments/approval:

Teresa Marie-Peyton Tawil 21950 Green Hill Rd. Farmington Hills, MI 48335

Title of Proposal "GENDER DIFFERENCES IN FREQUENCY OF ASSISTANCE AND PERCEIVED ELDERLY PATIENTS' LEVEL OF NEED BY SPOUSE PRIMARY CAREGIVERS WITH THE ACTIVITIES OF DAILY LIVING: BATHING AND DRESSING"

Does this proposal have an MSU ORD Number? No

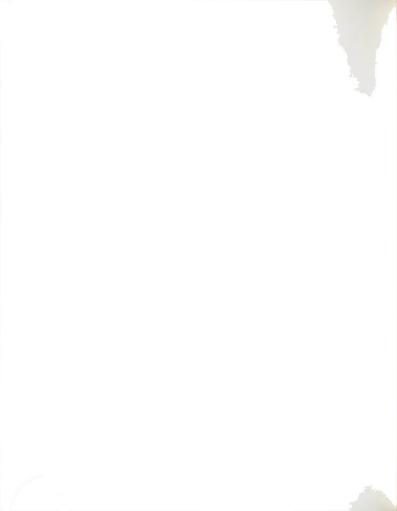
#### CATEGORY

b. This proposal is eligible for expedited review, category 2-I. (Research on individuals or groups behavior or characteristics of individuals....does not manipulate subjects' behavior and the research will not involve stress to subjects).

The data for this thesis is secondary data from a longitudinal study conducted from 1990-1992 by Coprincipal investigators: Charles W. Given Ph.D., Department of Family Practice, College of Human Medicine & Barbara A. Given, Ph.D., R.N., F.A.A.N., College of Nursing.

ABSTRACT

The demographics of caregivers are changing, and research must anticipate these changes to assist the Clinical Nurse Specialist in maintaining pertinent and effective interventions in the homecare situation. Because of the importance of both men and women as spouse primary caregivers, this study on spouse caregiver assistance will focus on the difference between genders to seek an understanding of contemporary spouse primary caregivers of the elderly disabled. The purpose of this study is to conduct secondary data analysis to explore gender differences in spouse primary caregivers' frequency of assistance, and perceived elderly patients' level of need with the activities of daily living: Dressing and bathing.



# PROCEDURES

The data for this thesis is secondary data from the longitudinal study "Responses to Managing Elderly Patients at Home", NIA Grant #2 RO1 AG06584-04, (Co-principal investigators: Charles W. Given Ph.D., Department of Family Practice, College of Human Medicine at Michigan State University, & Barbara A. Given, Ph.D., R.N., F.A.A.N., College of Nursing). The data were collected through the Center for Survey Research at Michigan State University by a trained telephone interviewer who recorded the interview directly into the computer database. The applicable data for this thesis will be provided via floppy disk.

Data analysis will involve crosstabulation through utilization of the program SPSSX. First, the gender will be crossed with the caregiver's perception of the elderly disabled patients level of need with the activities of daily living: Dressing and bathing. Second, the caregiver gender will be crossed with frequency of assistance with the activities of daily living: Dressing and bathing.

# SUBJECT POPULATION

- a. May include ... Incompetent Persons (or those with diminished capacity)? participants must be cognitively intact to complete the telephone interview. Functional ability is not applicable.
- b. Number of subjects (including controls) <u>336</u> <u>spouse caregivers.</u>

#### RECRUITMENT PROCEDURES

If someone will receive payment for recruiting subjects, please explain the amount of payment, who pays it and who receives it.

-Not applicable as this thesis utilizes secondary data. Will the research subjects be compensated?

-No monetary reimbursement was provided. A periodic newsletter and small gifts (mugs, pens etc.) were mailed to participants of the parent longitudinal study during various waves.

Will you be advertising for research participants?

-Not applicable as this thesis utilizes secondary data.

#### ANONYMITY/CONFIDENTIALITY

**Confidentiality** is provided by using identification numbers on the instruments for data collection, releasing research data in aggregate form only, by omitting agency names and/or identification in all reports, and by not providing confidential interview data to the recruiting agencies. In addition, all interviewers were carefully instructed in appropriate interviewing techniques, including the ethics of research, and were monitored by the Principal investigators throughout the study on a regular basis.

## RISK/BENEFIT RATIO

**Risk/Benefit Ratio** is apparent as the spouse primary caregivers behavior was not manipulated in any way, nor has any financial costs to the resulted from participation in this study. Potential psychological or social stress to the was safeguarded by assuring the confidentiality of the interview and the freedom to refuse to participate or withdraw from the study at any time. The potential benefits to the participants are their increased understanding of the spouse primary caregiving situation as well as their opportunity to express their thoughts and feelings to an objective person in a confidential manner. The potential benefits to the researcher, other health care providers and policy makers, is the increased understanding of the spouse primary caregivers participation with ADL's for the disabled elderly.

#### CONSENT PROCEDURES

Informed Consent procedures entail an initial written authorization given to the spouse primary caregivers by home care agencies to be contacted by the parent longitudinal study research staff. The home care agency personnel have previously determined subject eligibility and provided a description of the parent longitudinal study. Those subjects who agreed to be contacted were telephoned by the research staff. The parent longitudinal study was discussed in detail and the caregiver had the opportunity to ask Those caregivers who agreed to participate were questions. sent a consent form for their signature and return in an enclosed stamped addressed envelope. Subjects were informed both verbally and in writing, of their right to withdraw from the study at any time.

# MICHIGAN STATE

July 9, 1993

TO: Teresa Tawil 21950 Green Hill Rd Farmington Hills, MI 48335

RE: IRB #: 93-323 TITLE: GENDER DIFFERENCES IN FREQUENCY OF ASSISTANCE AND PERCEIVED ELDERLY PATIENTS' LEVEL OF NEED BY SPOUSE PRIMARY CAREGIVERS WITH THE ACTIVITIES OF DAILY LIVING: BATHING AND DRESSING CATEGORY: 2-1 REVISION REQUESTED: N/A APPROVAL DATE: July 1, 1993

The University Committee on Research Involving Human Subjects' (UCRIHS) review of this project is complete. I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and methods to obtain informed consent are appropriate. Therefore, the UCRIHS approved this project including any revision listed above.

UCRIHS approval is valid for one calendar year, beginning with the approval date shown above. Investigators planning to continue a project beyond one year must seek updated certification. Request for renewed approval must be accompanied by all four of the following mandatory assurances.



- 1. The human subjects protocol is the same as in previous studies.
- 2. There have been no ill effects suffered by the subjects due to their participation in the study.
- 3. There have been no complaints by the subjects or their representatives related to their participation in the study.
- 4. There has not been a change in the research environment nor new information which would indicate greater risk to human subjects than that assumed when the protocol was initially reviewed and approved.

There is a maximum of four such expedited renewals possible. Investigators wishing to continue a project beyond that time need to submit it again for complete review.

UCRIHS must review any changes in procedures involving human subjects, prior to initiation of the change. Investigators must notify UCRIHS promptly of any problems (unexpected side effects, complaints, etc.) involving human subjects during the course of the work.

If we can be of any future help, please do not hesitate to contact us at (517) 355-2180 or FAX (517) 336-1171.

Sincerely, David E. Wright, Ph.D.

UCRIHS Chair

DEW:pjm

MSU is an affirmative-action, equal-opportunity institution.

cc: Dr. Barbara A. Given

OFFICE OF RESEARCH AND GRADUATE

(UCRIHS)

STUDIES University Committee on Research Involving Human Subjects

Michigan State University 225 Administration Building East Lansing, Michigan 48824-1046 517/355-2180 FAX: 517/336-117C



INVOLVEMENT

APPENDIX F

### APPENDIX F

#### INVOLVEMENT

The next set of questions addresses the PRESENT level of performance for the person you care for on a number of activities and the way YOU AND OTHER PEOPLE help him/her. For each item, please choose the response that most closely describes the patient's PRESENT condition and how you assist him or her.

INTERVIEWER: <u>OTHER PEOPLE</u> category may include assistance from agencies, paid helpers, and family and friends. The purpose of these questions is to assess <u>current</u> involvement. CLARIFICATION --"Generally speaking over the past month ..."

#### DRESSING

[INTERVIEWER: CATEGORY DEFINITIONS ARE MEANT FOR PURPOSES OF CLARIFICATION]

This category includes the entire process of dressing or being clothed, including change from bed clothing into the set of clothing worn during the day, and change to bed clothing at night. This category DOES NOT include management of clothing during toileting. <u>If your relative</u> <u>always wears bed clothing during the day the answer "NEVER</u> <u>DRESSED".</u> Select the category that best describes your relative's level of functioning for DRESSING.

- 1a. With regard to dressing, would you say (\_\_\_\_\_)
  ... (CHECK ONE)
  - IS INDEPENDENT -- (does not need help of another person in any part of this activity.) (GO TO ITEM #2).
  - NEEDS SUPERVISION ONLY -- (requires another person present during the activity to instruct or watch for problems, but does not need the physical help of another person.)

\_\_\_\_ NEEDS SOME PHYSICAL HELP -- (requires physical help and the presence of another during all or part of this activity.) CARE RECIPIENT PARTICIPATES.

- NEEDS TOTAL PHYSICAL HELP -- (needs another person to carry out this activity.) CARE RECIPIENT DOES NOT PARTICIPATE.
- \_\_\_\_ IS NEVER DRESSED

(The next set of questions is about how frequently you and other people help your relative/friend with dressing.)

1b. How frequently do you help the patient with dressing? (CIRCLE ONE)

NEVER	ONCE A WEEK	SEVERAL TIMES	ONCE A	SEVERAL TIMES
	OR LESS	A WEEK (2-6)	DAY	A DAY

INTERVIEWER: "Help" includes any combination of supervision, some physical help, and total physical help.

#### 2. BATHING

This category includes all activities of bathing, whether tub or shower or bed bath: entry into tub or shower, wetting, soaping, rinsing, exit, drying body. Bathing DOES NOT include washing of head, drying hair, dressing or undressing. Select the response that best describes your relative's level of functioning for bathing.

- 2a. With regard to bathing, would you say (\_\_\_\_\_) ... (CHECK ONE)
  - IS INDEPENDENT -- (does not need help of another person in any part of this activity.) (GO TO ITEM #2).
  - NEEDS SUPERVISION ONLY -- (requires another person present during the activity to instruct or watch for problems, but does not need the physical help of another person.)
  - \_\_\_\_ NEEDS SOME PHYSICAL HELP -- (requires physical help and the presence of another during all or part of this activity.) CARE RECIPIENT PARTICIPATES.
  - NEEDS TOTAL PHYSICAL HELP -- (needs another person to carry out this activity.) CARE RECIPIENT DOES NOT PARTICIPATE.

(The next set of questions is about how frequently you and other people help your relative/friend with bathing.)



2b. How frequently do you help the patient with bathing? (CIRCLE ONE)

NEVER	ONCE A WEEK	SEVERAL TIMES	ONCE A	SEVERAL TIMES
	OR LESS	WEEK (2-6)	DAY	A DAY



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