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GENDER DIFFERENCES AMONG SPOUSE CAREGIVERS OF PERSONS WITH DEMENTIA IN DISTRESS ASSOCIATED WITH CAREGIVING TASKS

By

Kathy D. Reid

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ABSTRACT

GENDER DIFFERENCES AMONG SPOUSE CAREGIVERS OF PERSONS WITH DEMENTIA IN DISTRESS ASSOCIATED WITH CAREGIVING TASKS

By

Kathy D. Reid

The purpose of this study was to determine if husband and wife caregivers experience differing levels of distress in relation to specific caregiving tasks. A secondary analysis of data taken from the study "The Impact of Alzheimer's Disease on Family Caregivers" is used to answer the proposed study question, (Clare Collins, Ph.D., Principal Investigator, Grant #2R01-MH-41766, IRB 88-442). While the original study utilized a longitudinal survey design, only spouse caregiver respondents interviewed during Wave II were selected for inclusion in this study. Socio-demographic differences noted between the two groups of caregivers were related to caregiver age and care recipient disability. Statistical analysis revealed no significant differences between husband and wife caregivers in level of distress associated with specific tasks or groups of caregiving tasks. Multivariate analysis revealed time involvement with caregiving tasks as a significant influence on caregiver distress.

To Marshall, Derek and Ryan

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Background of the Problem

The United States is experiencing considerable growth in its elderly population (Rice et al., 1991). Current projections estimate that by the year 2010, more than 40 million Americans will be 65 years of age and older (U.S. Dept. of Commerce, 1994). As the number of elderly increase, so will the demands on the health care delivery system. In turn, health care providers will need to enhance their knowledge of the needs of this diverse population particularly with regard to medical and mental health concerns.

As the elderly population grows, the cognitive disorders commonly referred to as dementia processes will be of interest to health practitioners (Office of Technology Assessment, 1987). Dementias are among the most common cognitive disorders found among the elderly (Reifler, 1990), and have grown into a major public health issue (OTA, 1987). Alzheimer's Disease is the most common type of dementia (comprising approximately 66% of all dementia cases), and is the fourth leading cause of death among the over 65 age group in the United States (OTA, 1987). Persons with dementia such as Alzheimer's Disease become increasingly unable to fill social roles and ultimately become dependent on others for assistance with activities of daily living (Pallett, 1990).

Family members, particularly spouses, are the primary caregivers for patients with Alzheimer's Disease in this society (Wilhoite & Buschmann, 1991). Spouse caregivers often face an overwhelming task and, although not all will suffer adverse outcomes from the caregiving experience, they are at risk for diminished health and psychological well-being (Collins, Stommel, Given, & King, 1991; Given, Collins, & Given, 1988).

There is a vast amount of literature available on experiences and outcomes of caregiving. Within the literature, there has been growing interest in the reactions of caregivers to caregiving experiences with some researchers focusing specifically on spouse caregivers. The literature has explored differences among husband and wife caregivers and looked at the influence of gender differences among spouse caregivers in response to caregiving. In addition, spouse caregiver reactions such as burden and distress associated with the caregiving experience have been examined (Fitting, Rabins, Lucas, & Eastham, 1986; Zarit, Todd, & Zarit, 1986; Pruchno & Resch, 1989).

Based upon the internal nature of the relationship, the expectations and commitments of caregiver-recipient bonds differ (Pallet, 1990). The relationship of the spouse caregiver-recipient is recognized as an intimate connection that may influence outcomes of caregiving in ways that are different from other caregiver-recipient bonds. Additionally, differences among male and female spouse caregivers may influence their response to caregiving demands. Differences, such as the way husbands and wives perceive their social environments and social support network, perception of their relationship with the care-recipient, and amounts of time carrying out caregiving activities, have been explored for their impact on the caregiving role (Fitting, et al., 1986; Enright, 1991). The literature also explores such concepts as gender and the effect gender differences may have on response to caregiving among husband and wife caregivers (Lutzky & Knight, 1994).

Gender differences have been recognized as major contributors to the way in which the caregiver responds to the caregiving experience (Young & Kahana, 1989). Research has also contributed information regarding differing types of caregiving activities performed by husband and wife caregivers (Stone, Cafferata, & Sangl, 1987) and use of outside support resources (Pruchno & Resch, 1989).

There are reports of caregiver reactions such as stress, distress, burden, and coping (Given, et al., 1988; Neundorfer, 1991; Gallagher-Thompson, Brooks, Bliwise, Leader, & Yesavage, 1992; Wilson, 1989). Such reactions are described as general responses to caregiving and the terms are often used interchangeably in the literature. These global reactions have been studied as they relate to specific aspects of caregiving such as the impact of caregiving on interpersonal relationships, social activity, and finances (Barusch & Spaid, 1989; Moritz, Kasl, & Berkman, 1989; George & Gwyther, 1986) .

Researchers have attempted to discover which variables involved in caregiving have a significant relationship to caregiving outcomes. For example, researchers have evaluated the impact of assistance with different groups of caregiver tasks and the influence of these caregiving activities on response to caregiving. Factors involved in the stress process and how they relate to consequences for a caregiver's physical and emotional health are highly variable.

Although the types of problems requiring assistance from caregivers and the caregiver's reaction to those problems differ greatly, many researchers have failed to account for these differences (Neundorfer, 1991).

Statement of the Problem

Despite multiple studies on global reactions to caregiving, and response to caregiving as influenced by assistance with defined groups of caregiving tasks, little is known about the reactions of the spouse caregiver to specific caregiving tasks within these groups. Little is known about differences among husband and wife caregivers and the amount of distress they experience when providing help to their spouse with specific caregiving tasks. It is important to understand the impact of caregiving on the spouse in order to best influence positive outcomes of care. Activities that are particularly stressful for the spouse caregiver may negatively influence coping and, in turn, influence their ability to maintain themselves in a primary caregiving role. Increasing the knowledge base in this area will enhance the development of successful intervention strategies and will foster a successful caregiving experience.

The spouse caregiver-recipient relationship and gender differences among spouse caregivers may both influence how the caregiver participates in the caregiving role and, in turn, how the caregiver reacts to the caregiving experience. The purpose of this study is to determine if husband and wife caregivers differ in the level of distress experienced when providing assistance with specific caregiving tasks for a spouse with dementia. The hypothesis for this study is that a differing level of distress will be experienced by husband and wife caregivers in relation to specific caregiving tasks.

Review of Literature

Caregiving Tasks

The term dementia implies global impairment in mental function. Symptoms may include memory loss, loss of language functions, impairment in abstract thinking ability, personality change, apraxia leading to decreasing ability to care for oneself, and emotional instability. Dementia patients may experience spatial disorientation and motor disturbance, as well as anxiety, mood, and sleep disorders. In addition, individuals with dementia encounter difficulties performing daily activities such as dressing and cooking, planning, initiating, and carrying out activities such as work and budget planning. They may use poor judgment, lack insight, and be at risk for physical injury (DSM-IV, 1994; OTA, 1987).

Because of the manifestations resulting from dementia, individuals with the disorder will, at some point, require assistance with daily living tasks. During the later stages of the disease, patients may require various amounts of help throughout the day and night with such activities as eating, grooming and toileting (ADRDA, 1990).

The literature describes activities associated with the care of persons with dementia as activities of daily living (ADL), instrumental activities of daily living (IADL), and behavioral symptoms associated with the disease (Given, et al., 1988; Moritz, Kasl, & Berkman, 1989; Vitaliano, Russo, Young, Teri, Maiuro, 1991; Zarit, Todd, & Zarit, 1986; Haley & Pardo, 1989). In addition, Rice et al. (1991) add the category of aid provided by caregivers in social/recreational activities.

Haley and Pardo (1989) described and measured three caregiving activity categories as a means for assessing patient impairment and caregiving coping and adjustment. Activities of daily living measures were defined as those tasks requiring assistance due to an impairment in basic self-care behavior (e.g. continence, transfers, bathing, and ability to feed oneself). Instrumental activities of daily living were designated as those tasks requiring assistance due to an impairment in higher level self-care skills (e.g. ability to use the telephone and manage one's finances). Behavior problems were defined as those troubling or disruptive changes in one's personality or behavior requiring intervention on the part of the caregiver.

For the purpose of this thesis, caregiving tasks will be defined as the categories outlined above; ADL (assistance with personal care, including bathing, toileting, feeding, getting dressed; and assistance with mobility including walking, and getting in and out of bed), IADL (providing transportation; managing finances; assistance with household tasks such as laundry, cooking, and cleaning; assistance with tasks outside the home such as shopping and running errands), and behavioral problems (confusion and memory loss, and providing emotional support). Since caregivers may find themselves frequently involved in the social/recreational needs of the dementia patient, the category of caregiver activity (including the structuring/planning of activities such as recreation, meals, and rest, and coordinating, arranging, and managing services and resources) is integral to discussion within this paper and described here as an additional set of caregiving tasks often facing the dementia caregiver. In addition, it is important to recognize caregiving activities associated with the health care needs of persons with dementia, hence the category health care activities (medical or nursing treatments such as giving medications, changing dressings, skin care, exercises, etc.; and monitoring and reporting symptoms and progress) is included here as another category of caregiving activity worthy of discussion.

Global and Specific Reactions to Caregiving

There is a large volume of literature that examines caregiver reaction to the caregiving role. The literature describes these reactions by the use of such terms as subjective burden, stress and the mental health outcomes of caregiving like depression and anxiety. Given, et al., 1988, conceptualized caregiver reactions as "psychological responses" (p. 77) that influence the nature of caregiving relationships and impact the physical and emotional health of the caregiver. Interests have focused on the effects of the overall caregiving experience and on which aspects of such experiences influence caregiving outcomes.

Although the caregiver's response to caregiving has received considerable attention in the literature, some confusion remains about the way in which the short and long term nature of these reactions are defined. Caregiver burden is most often discussed as specific to the caregiving role. Caregiver burden has been measured by a number of researchers who attempt to describe caregiver reaction in relation to activities of caregiving. Poulshock and Deimling (1984) describe burden as it refers to the subjective experience that certain caregiving tasks are considered stressful or burdensome.

Grafstrom, Fratiglioni, Sandman, and Winblad (1992) discuss burden interchangeably with the term "psychological stress" (p. 868) as a means for describing caregiver reaction to living with a family member who has a dementing disease. Burden has been used to describe mental health outcomes of caregiving and caregiver burden has been associated with increased stress symptomatology, poorer self rated health, affect balance and life satisfaction among caregivers (George & Gwyther, 1986). Most generally, burden is seen as a short term outcome of the caregiving experience and, when allowed to persist, may lead to more global long term effects such as depression and anxiety.

Depressive symptomatology has been associated with caregiver tasks and patient cognitive function (Moritz, et al., 1989). Caregiver stress related to a cognitively impaired person's memory and behavior problems has been found to be predictive of caregiver depression and anxiety (Neundorpher, 1991). Neundorpher (1991) discussed the perceived stressfulness of patient problems and coping efforts as a means for evaluating the caregiver's physical health, and depression and anxiety associated with caregiving. Others have described caregiver reactions by comparing stress symptoms of the family caregiver with those not caring for family members with dementing disease. George and Gwyther (1986) found the dementia caregivers in their study had three times as many stress symptoms as their community counterparts not caring for cognitively impaired individuals.

According to Webster's Third World Dictionary (1976) distress "commonly implies conditions or circumstances that cause physical stress or strain, suggesting the need for assistance; in application to mental state, it implies the strain of fear, anxiety, shame or the like (p.660)". A small body of caregiving research uses the term "distress" as a means for describing reaction to the caregiving experience.

Distress has been used as a collective term for discussing the reaction to anxiety or depression associated with caregiving (Novack, Bergquist, Bennett, & Gouvier, 1991), and has been used synonymously with caregiver burden by others (Tausig, 1992). Vitaliano, et al. (1991) discuss the concept of distress and use burden as an interchangeable term in defining its meaning. The authors suggest that distress (burden) is the end product of the interaction between exposure to stress, vulnerability, and resources. Knight, Lutzky, Macofsky-Urban (1993) define caregiver distress broadly to include "subjective burden, depression, anxiety, hostility, and other measures of negative affect" (p. 240).

Despite the fact that several researchers have described long term outcomes of caregiving such as depression as a manifestation of the caregiver role, others question whether outcomes such as depression might be associated with other variables outside of the caregiving experience. For example, although women tend to report increased levels of distress or burden with caregiving, they also report increased levels of depression in the non-caregiving population as well (Krause, 1986). Hence, it may be suggested that it is a predisposed tendency toward depression in women that leads them to react differently than men to the same caregiving events.

In summary, considerable variability exists in the literature among terms describing caregiver reactions. For the purpose of this study, caregiver distress is defined as a reaction to performing specific caregiving tasks. Such distress may lead to subjective feelings of burden which can be translated to more global long term outcomes such as depression and anxiety disorders. Because distress may lead to long term negative effects of caregiving, it is important to understand the spouse caregiver's subjective feelings of distress associated with the caregiving role, particularly when the distress experienced by assisting the spouse with dementia is associated with specific caregiving tasks.

There is a small body of literature that examines the distress experienced by dementia caregivers in response to specific caregiving tasks. Vitaliano, et al. (1991) used a longitudinal approach to evaluate the importance of care recipient and caregiver variables in anticipating distress among spouse caregivers. The authors found that baseline caregiver burden interacted with care recipient ADLs and that caregiver vulnerability interacted with available resources. Subsequently caregivers already burdened with more impaired care recipients were at greater risk for distress (burden). In a study of 140 dementia caregivers, Farran, Keane-Hagerty, Tatarowicz, and Scorza (1993), found that fewer caregivers reported distress associated with ADL and IADL tasks than activities associated with disruptive behaviors. Mean levels of distress reported in each of these categories was found to be low, with moderate levels of distress being reported for assistance with disruptive behaviors only. Findings indicated no significant relationships between level of care-recipient ADL impairment and caregiver burden. Despite the efforts of some to examine distress associated with general aspects of caregiving activity, no studies could be found that measured the distress associated with specific caregiving tasks.

Gender Differences in Response to Dementia Caregiving

While a significant amount of literature describes the general caregiver characteristics of the male and female caregiver of dementia patients and differences that exist among them, a smaller body of literature examines the differences between spouse caregivers. Although society's image of caregiving is as a largely female endeavor, with 67% of care provided by wives in spouse-caregiver relationships (Miller & Cafasso, 1992), it has been supported in the literature that husbands participate extensively in caregiving for their wives with dementing illness (Enright, 1991).

Research based on gender differences among caregiving spouses of patients with dementia addresses such topics as time spent providing care to a spouse with dementing illness, types of activities performed by husband and wife caregivers, help received from outside support sources, and mental health differences among male and female caregiving spouses. Enright (1991) found that while husbands and wives participate extensively in caregiving, they differ in the amount of help they receive with caregiving tasks. Non-employed wives in the study were found to receive less help from others with daily caregiving activities. Spouses with jobs, particularly husbands, received large amounts of outside help. Likewise Pruchno and Resch (1989) found caregiving husbands more likely than wives to be receiving help with direct physical care.

Pruchno and Resch (1989) suggest that the demands of the caregiver role are experienced differently by men and woman. In comparing the mental health outcomes of husband and wife caregivers, wives were found to be more depressed and experienced more burden than caregiving husbands. In contrast, Fitting, Rabins, Lucus, and Eastham (1986), report that while the woman in their study reported more depressive symptoms, husbands and wives experience similar degrees of burden, and appeared to experience their caregiver roles in similar ways overall.

While little was found in the dementia caregiving literature to describe tasks specific to the male and female caregiver, researchers in other areas of caregiving have found that men and women provide differing types of care. The following studies are mentioned here as a means for describing the types of caregiving activities in which each gender might engage. It is noted, however, that because of the cognitive changes associated with dementing illness, dementia caregiving situations may include additional task domains not discussed here, such as those tasks related to the behavioral management needs of dementia patients.

In a study of nonspouse caregivers, Stoller (1990), found that helping patterns among caregivers reflected the cultural division of labor based on sex. Woman were more likely to help with cooking, laundry, and routine household chores. Men were as likely as women to assist with shopping, financial management, and heavy chores. In general, women provided assistance with a broader range of tasks. Findings suggest that men were less frequently likely to assist with routine household chores, and more apt to be available for intermittent or occasional tasks. In a study of 183 heart patient caregiver dyads, findings were consistent in showing that female and male caregivers were likely to help with gender-specific tasks. Women were found to provide more assistance in general, assisting with tasks such as laundry and meal preparation;

males were more likely to assist with transportation and handiwork (Young & Kahana, 1989).

Barusch and Spaid (1989) report that male spouse caregivers are more likely to make use of home nursing, aide, and home delivered meal services. Men reported performing more tasks than woman, particularly in the areas of communication, mobility, hygiene, dressing and feeding. Again, women were found to report higher levels of burden than men. Similarly, Stone et al., (1987), found husbands to report that they spent the greatest number of extra hours with caregiving responsibility. Eighty-nine percent of husbands reported spending extra time on shopping and transportation, while 58% of wives reported spending extra time helping with money matters as compared to 42% of caregiving husbands.

Although several researchers suggest that gender differences may influence the caregiver's response to the caregiving experience, some controversy persists as to whether reported gender differences actually exist and, if so, the level of significance of such reports to clinical practice is questioned. Miller and Cafasso (1992), examined and compared a variety of caregiving literature with respect to gender differences. These authors maintain that published articles tend to emphasize statistically significant gender differences, while ignoring findings suggestive of the presence of no differences, in turn minimizing the clinical significance of study results. Through the use of meta-analysis techniques, these authors examined the combined findings from descriptive studies of gender differences in caregiving. Accumulated results across studies and an evaluation of the size and significance of gender differences in caregiver stress and burden were examined. The authors found no significant gender differences in functional impairment of the frail care recipient or total caregiver involvement in care. Woman were found more likely to carry out personal care and household tasks and were more likely to report greater burden. However, neither findings were significant enough to represent any real differences. A limitation of caregiver research is the inability to detect the relatively small differences between male and female caregiver activity. The authors attribute problems with interpretation of findings to conceptual and methodological limitations of caregiver studies to date.

Despite the focus in the literature on gender differences in caregiving, several questions remain that, when answered, may shed light on caregiver-recipient reaction to the caregiving experience. It may be helpful to understand to what extent the male and female differ in their enactment of the caregiver role (Miller & Cafasso, 1992), and to test for differences between the male and female spouse provider in reaction to specific caregiving activities. The literature is lacking in clinically based studies that describe the caregiving experience and in testing hypotheses that suggest caregivers use gender-related approaches to their role. The literature offers few guidelines for designing intervention programs sensitive to gender differences (Corcoran, 1992). In addition, no studies were found that addressed specific caregiver tasks and the relationship of these tasks to a gender based response to providing care.

While some literature demonstrates differences in types of tasks performed by the spouse caregiver based on gender and groups of tasks, less is known about differences between husband and wife caregivers in reaction to specific tasks within the groups. Little progress has been made to explain why these general responses exist for both the husband and wife provider and, whether or not, gender plays a significant role in differing response. Some speculate differences that do exist may be due to gender specific role expectations. This assumption may lead to biased interpretation of study findings and limit implications to clinical practice situations. Because some study results contradict traditional thought on gender specific tasks, and make it unclear as to what gender specific caregiving tasks exist among spouse caregivers, this author proposes the need for further investigation in this area.

Summary

As dementia impairs a person's ability to function independently, she or he will need assistance to maintain daily activities. Such activities may include daily living tasks, management of behavioral symptoms associated with the disease, and the social implications manifesting in the process. Family members, particularly spouses, are often the primary informal providers of care for dementia patients. Because spouses of dementia victims are often elderly and frail themselves, they are at risk for potential health outcomes produced by the physical and emotional stress and strain brought about by the caregiving experience. Spouse caregiver reaction to the manifestations of caregiving may lead to affect imbalance and influence their overall sense of well being. Gender differences among husband and wife caregivers are likely to influence the response to caregiving. While the literature addresses the response of the caregiver to various general caregiving responsibilities it fails to describe these activates in more specific terms. Little is known about the spouse caregiver's response to specific caregiving tasks or about gender differences among spouse caregivers and the distress produced by performing these specific activities.

Clinical nurse specialists (CNS) working with the geriatric population are in a key position to assist the older spouse to cope with the distress produced by dementia caregiving. Assistance with specific caregiving tasks may promote a more positive response to the caregiving experience. The CNS can enhance the understanding of role stress and strain and, in turn, promote positive self care behaviors on the part of caregivers. In collaboration with other members of the health care team, the CNS can share accountability for planning for the needs of dementia caregivers and care recipients within their community, or within health care systems in general. In so doing, the CNS acts as a change agent by systematically bringing about positive alterations in health care systems and in the communities which they serve. By identifying the health needs of caregivers and implementing a therapeutic plan of treatment, the CNS is able to coordinate the structure of the caregiving situation and evaluate caregiver effectiveness. And by assuming the role of educator, the nurse in advanced practice can teach both caregivers and health care providers how to effectively manage the demands of the caregiving role, and enhance a positive response to caregiving.

Conceptual Model

Sources of stress experienced by family caregivers of patients with dementia are variable and may positively or negatively influence the caregiver's response to caregiving. As a means for understanding the stress and strain of caregiving, Given, Collins, and Given (1988) developed a model that describes factors influencing caregiver response to caregiving. Although this model has not been tested in the literature, it offers a clear picture of the complex interrelationships among variables that influence caregiver response and is useful as a means for understanding the concepts introduced with this research. The model will be used to guide the discussion of caregiver distress as experienced by spouse caregivers in relation to specific caregiving tasks, and as a means for understanding the influence of gender on caregiver reaction to providing care to individuals with dementia.

The model depicts the complexity of the relationships among variables which have a bearing on the caregivers reaction to the overall caregiving experience (Fig. 1). The authors suggest that factors such as the type and quality of the prior caregiver-recipient relationship, and patient and caregiver characteristics, influence the caregiving environment and determine the initiation and maintenance of the caregiving role.

Patient characteristics such as severity of disease with resulting symptoms and deficits such as cognitive dysfunction, disruptive behavior, impaired social functioning, and need for assistance with daily activities interact with caregiver characteristics such as caregiver gender, personality traits, and defined role obligations. As these caregiver and patient characteristics interact, they ultimately impact the caregiving relationship.

The type and quality of the previous caregiver-recipient relationship relates to such elements as kinship and how the caregiver and care receiver maintained and valued their previous interaction. The caregiving environment is integral to the overall quality and direction of the caregiving relationship. It is most influenced by the social support the caregiver perceives as available, community services used, and the financial conditions imposed by caregiving. Caregiver interpretation of the caregiving environment will be based on the caregiver's perception of the quality and availability of support services.

The way caregiver/patient characteristics and prior relationship issues support the caregiving environment will influence the caregiver's response to caregiving. These reactions, in turn, impact caregiver physical and mental health. The model depicts a constant interplay between these reactions and the maintenance of the caregiving role. Caregiver physical and mental health have the capacity to impact the caregiving role as a continuous interaction with the caregiver's response to caregiving.

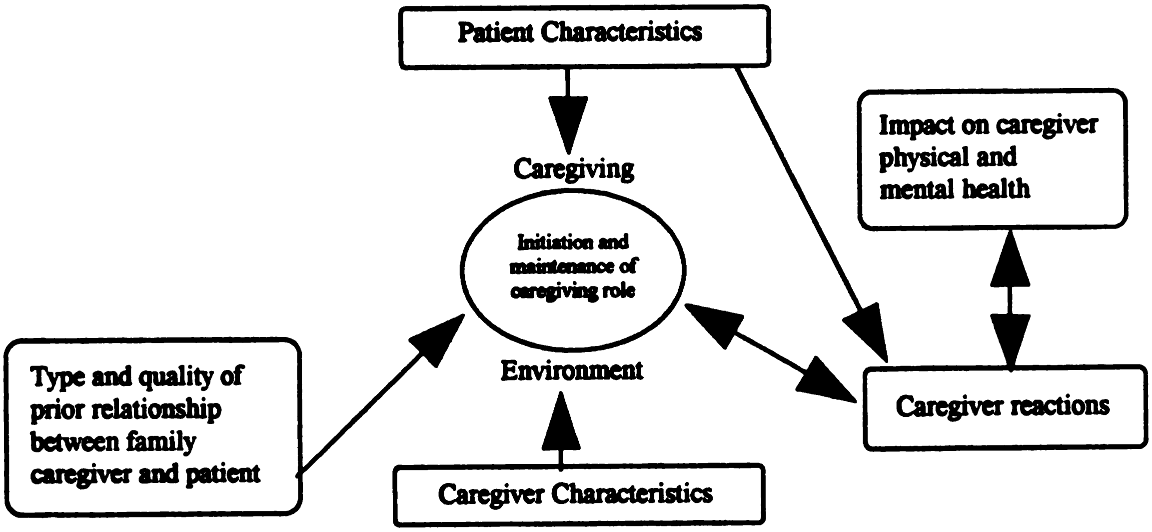

Figure 1 - Factors influencing caregiver responses to the patient with AD (Given, Collins, & Given, 1988)

Caregiver reactions are conceptualized by the authors as "psychological responses" to the caregiving role. These reactions will determine the ongoing nature of the caregiving experience as they interact with the caregiving environment and the health of the caregiver. Caregiver reactions have been classified as negative and positive reactions, impact on schedule and health, feelings of family abandonment, and role responsibility.

The purpose of this thesis is to examine distress associated with specific caregiving activities, and to determine if male and female caregivers differ in the level of distress experienced with specific caregiving tasks. The caregiving model described above has been adapted as a means to explain the interaction among variables that may influence the level of distress experienced by the caregiver and associated with the caregiver role (fig. 2). The adopted model considers the indirect link between caregiver characteristics and caregiver reactions through the initiation and maintenance of the caregiving role. This link is integral to understanding the relationship between caregiver characteristics and caregiver reactions. The need for help with specific caregiving tasks is recognized as a patient characteristic and gender is recognized as a caregiver characteristic that, through a complex interaction, will have an impact on the way in which the caregiver responds to a particular caregiving situation. Caregiver reactions to the need to help the person with dementia with various needs may be manifest in the form of distress. Distress will be recognized as a negative reaction that influences the physical and mental health of the caregiver. This subjective emotional response is in constant interaction with the caregiving environment and is seen as integral to the maintenance of the caregiving role. It is recognized that gender may influence the way in which the caregiver interprets the demands of his or her role, particularly in relation to the specific type of activity in which the caregiver may engage. Caregiver perception of the caregiving experience will be influential in determining an overall reaction and will, in turn, play a decisive role in the maintenance of caregiver health.

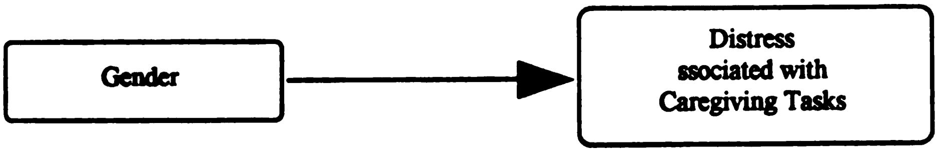

Figure 2- (Adaptation of Caregiving Model from Fig.1, Given, Collins, & Given, 1988).

Methods

Data used to answer the proposed research question was taken from the study "The Impact of Alzheimer's Disease on Family Caregivers". This study was funded by the National Institute of Mental Health and took place between 1988 and 1992.

Study Design

The original study "The Impact of Alzheimer's Disease on Family Caregivers" utilized a longitudinal survey design with three measurement points across a four year study period. The intent of the original study was to measure changes in caregiver reactions, mental and physical health, changes in patient characteristics, community service use, service availability, caregiver reactions to patient institutionalization, and bereavement reactions of caregivers over time. For the purpose of this thesis, a secondary analysis of data collected from this larger study will be carried out in order to answer the proposed study question.

Sample

A convenience sample of 210 caregivers providing care to family members with dementia in the community setting were recruited during Wave II of the original study. This sample is used for the purpose of data analysis carried out as part of the research described in this thesis. Subjects were recruited via mailings to potential participants located through the Alzheimer's association and various health agencies in south west Michigan. These agencies distributed a description of the study along with a postcard to the potential participants. The postcard was to be returned to the principal investigator indicating the interest of the respondent to participate in the study. The caregivers who indicated interest in study participation were then screened over the telephone by trained interviewers to determine study eligibility. Subjects meeting the following criteria were included in the study: 1) the caregiver had to identify himself as the family member who provided the most care to a relative with Alzheimer's disease or a related dementia; 2) the relative with dementia was at least 55 years old; and 3) dependent in at least one activity of daily living (ADL) and one instrumental activity of daily living (IADL); 4) the family member had received a diagnosis of Alzheimer's disease or related dementia (as reported by the caregiver; no other confirmation of diagnosis was made); 5) the patient and caregiver were residing in the community at the time of entry into the study. For the purpose of this study, a smaller sample consisting of only the spouse caregivers (n=118) were selected out of the larger sample for inclusion in data analysis.

Data Collection Procedures

Prior to data collection, members of the sample were told that they would be participating in a longitudinal study that involved contact by investigators at three different points in time, over the four year study period. Individuals involved in this study were asked to participate in a one and one-half hour telephone interview and to complete a mailed, self-administered booklet at each of the three measurement points. Data collection activities were carried out in conjunction with the Center for Survey Research at Michigan State University (Collins, 1993). The Human Subjects procedures were approved by the University Committee on Research Involving Human Subjects at Michigan State University.

Protection of Human Subjects

Members of the sample were informed of the confidentiality of the information gathered in this study. Each participant signed a written informed consent prior to their participation in the study. The original study was approved by the University Committee on Research Involving Human Subjects at Michigan State University. Approval for secondary analysis of data collected during the original study was obtained from the University Committee on Research Involving Human Subjects (UCRIHS-see Appendix B). No subject identifiers were included with the secondary data.

Operational Definition of Variables/Instrumentation

For the purpose of this study, caregiving tasks are operationalized as described in the twelve questions that make up the "Caregiver Activity" self-administered questionnaire. The Caregiver Activity Scale (Collins,1993), will be used as a means for examining time spent on the part of spouse caregivers performing various activities and as a means for measuring caregiver distress associated with these activities (See Appendix A). This scale is an adaptation of the Caregiver Load Scale (CLS) developed initially as a means for measuring time and energy family members expend in caregiving activities (Oberst, Thomas, Gass, & Ward, 1989). The Caregiver Load Scale consisted of 10 frequently reported caregiver tasks including medical/nursing treatments, personal care, assistance with mobility, emotional support, monitoring and reporting, provision of transportation, managing illness-related finances, additional household tasks, structuring activities, and managing behavior problems. Initial content validity of the scale was assessed using a panel of seven caregivers engaged in caring for a family member with Alzheimer's disease, and a panel of six clinical experts who made suggestions for revision of the scale to ensure that items reflected the intended appraisal as accurately as possible. Respondents were asked to respond to each item contained in the questionnaire using a single five-point scale with response choices ranging from a great deal of time and energy to little or no time and energy. The CLS was further modified as a means for measuring time spent in caregiving (demand), and amount of difficulty associated with each of 14 frequently reported caregiving tasks (Carey, Oberst, McCubbin, & Hughes, 1991). This Caregiving Burden Scale (CBS) asked for subjects to respond twice to items on five-point scales as ranging from little or no to a great deal of time spent in providing a particular activity (demand scale) and little or no to a great deal of difficultly associated with the specific activity. A burden score was calculated for each item by multiplying demand by difficulty. Caregiving activities added from the original CLS to the CBS included running extra errands, coordinating/scheduling, assisting with communication, and increasing care for others. For information on the CLS as discussed above relative to reliability of the previously tested demand scale, and for validation of caregiving activities refer to Oberst, et al., 1989. The difficulty scale and burden score had not been previously tested.

The CBS has been slightly modified for the purpose of this study (see Appendix A). Caregivers responding to the Caregiver Activities Scale were asked to respond twice to a single five-point scale ranging from little or none (=1) to a great deal (=5) of time spent performing each of twelve caregiving activities (time) and little or none (=1) to a great deal (=5) of distress experienced performing each specific activity. The frequency scores related to the category little to none (=1) for both distress and time associated with each caregiving task is ambiguous. It is impossible to unambiguously sort out those caregivers who experienced no distress or who did not participate at all in a particular task from those who did. Therefore, all five possible response categories for both distress(ranging from a great deal (=5) to little or none (=1)) and time spent with each task (ranging from a great deal (=5) to little or none (=1)) are included in the data analysis.

For the purpose of this study, distress is operationalized as the subjective response by study participants to questions on the "Caregiver Activity" self-administered questionnaire. In addition, time is operationalized as ordinal level estimates of the amount of time the caregiver spends performing each specific caregiving activity.

Caregiving activities requiring response include medical or nursing treatments; personal care; assistance with walking, getting in and out of bed, etc.; emotional support; monitoring and reporting symptoms and progress; providing transportation; managing finances, bills, and insurance forms related to the illness; additional household tasks; additional tasks outside the home; structuring/planning activities; managing behavior problems; and coordinating, arranging, and managing services and resources. Currently there is no reliability or validity information available on this version of the scale. Validity of the instrument is supported by its consistency with the literature by including common accepted caregiving activities and as described in previous versions of the scale. In addition, input from clinical experts and caregivers in the construction of the original instrument helps to ensure the ability of the scale to measure what it is intended to measure. Gender is operationalized by categorizing sample participants by sex (male and female).

For the purpose of this research, two new scales were created using existing study variables. The first scale is a measure of ADL dependency that included eight personal care or mobility activities for which the caregiver rated the care-recipient in terms of whether or not he or she could perform them independently, with supervision only, or with some or total physical help. The activities include getting dressed, grooming, bathing, toileting, eating, as well as walking, transferring or getting in and out the house (see Appendix C). A Cronbach's alpha of .94 reveals the very high internal consistency of this measure. The second scale is a measure of cognitive impairment in which the caregiver was asked to judge the care-recipient on seven different abilities including orientation, judgment, memory, wandering, awareness of own needs, night needs, and general supervision (see Appendix D). Responses to these items again revealed substantial internal consistency (Cronbach's alpha=.84) suggesting that the scale is a reliable measure of patients' cognitive disability.

Extraneous Variables

It is recognized that a variety of extraneous variables may effect the level of distress experienced by caregivers. While the influence of gender on caregiver distress associated with caregiving tasks may be evident through various statistical analyses, it is important to consider other variables that may also affect the reaction to the caregiving experience. For example, the caregiver's level of involvement with regard to the type and amount of time spent with each task may influence the amount of distress he or she experiences. In addition, it is important to consider the level of disability of the care-recipient, including the level of cognitive impairment and the length of time the caregiver has participated in caregiving, as these variables may be equally as predictive of caregiver reaction as gender itself. Such background caregiver characteristics such as age, educational level, and socioeconomic status are also worthy of study because they may, in turn, have an impact on the caregiving situation as well. As part of the statistical analysis of this study, the characteristics of the combined group of caregivers, as well as the male and female groups were described and examined.

Results

Socio-demographic Characteristics

Table 1 presents demographic characteristics of the combined caregiver sample, as well as the female and male groups of caregivers separately. The combined group of spouse caregivers who make up the study sample are predominantly white (96%), female (68%), and all reside with the care recipient in the same household. The majority of the sample (84%) consists of the caregiver-care recipient dyad without other persons residing in the same household. Eighty-two percent of the combined sample has a high school, or higher education, with a mean yearly family income of $27,909.48. The average length of time involved in the caregiving situation is 5.6 years. The average age of the caregiver is 68 years, while the average age of the care recipient is 71 years.

The two groups of husband and wife caregivers were compared using all available socio-demographic variables (see Table 1). As the significance values indicate, ($p < .05$ are generally deemed statistically significant), differences were found with respect to caregiver age. Female spouse caregivers are, on average, four years younger than male spouse caregivers. Care recipients of the male spouse caregiver demonstrated a higher level of cognitive impairment and a higher number of ADL dependencies. In addition, the variable number of persons living in the household was nearly statistically significant ($p=.055$) and warrants mentioning here while comparing the two groups of spouse caregivers. It is noted that 11% of female spouse caregivers lived in households consisting of 4 persons; none of the male spouse caregivers had households of this size. Male households were generally smaller, consisting of 2 to 3 persons. It is not clear from data analysis who made up the households that consisted of greater than 2 persons beyond the spouse couple. No other measured background characteristic shows a significant difference between the two comparison groups.

Table 1 - Demographic Variables for Spouse Caregiver Sample

Caregiver Characteristics	Combined Group (n=118)	Female Caregivers	Male Caregivers	Sig. Test for Difference *(t or Chi-square)*
Gender	118 (100%)	80 (100%)	38 (100%)	
Caregiver Age(yrs)				
Mean	67.60	66.08	70.78	p=.004
SD	8.36	8.44	7.31	
Caregiver Recipient Age (yrs)				
Mean	70.54	70.91	69.76	p=.444
SD	7.58	7.41	7.95	
Race				
White	113 (96%)	76 (95%)	37 (97%)	p=.551
Non-White	5 (4%)	4 (5%)	1 (3%)	
	118 (100%)	80 (100%)	38 (100%)	
Living Arrangements				
Lives with	118 (100%)	80 (100%)	38 (100%)	
Does not live with	0 (0%)	0 (0%)	0 (0%)	NA
	118 (100%)	80 (100%)	38 (100%)	
Number persons living in household				
2	99 (84%)	66 (83%)	33 (87%)	
3	10 (8%)	5 (6%)	5 (13%)	p=.055
4	9 (8%)	9 (11%)	0 (0%)	
	118 (100%)	80 (100%)	38 (100%)	
Household Income				
Mean	27,909	26,215	31,527	p=.146
SD	15,685	13,025	19,969	
Education				
Less than H/S	21 (18%)	14 (18%)	7 (18%)	
HS or higher	97 (82%)	66 (82%)	31 (82%)	p=.48
	118 (100%)	80 (100%)	38 (100%)	
Duration of care-giving (months)				
Mean	67.22	67.11	67.43	p=.975
SD	51.02	55.46	40.58	
Care Recipient Disability				
Cognitive Disability				
Mean	2.84	2.750	3.040	p=.027
SD	.67	.681	.607	
ADL Dependency				
Mean	2.45	2.28	2.80	p=.010
SD	1.05	1.02	1.04	

Gender and Distress with Specific Caregiving Tasks

The purpose of this study was to determine if husband and wife caregivers differ in the level of distress experienced when performing specific caregiving tasks. First, a discussion of the spouse caregiver's evaluation of the time spent with caregiving tasks is presented. Table 2 portrays the time spent with specific caregiving tasks by husband (N=38) and wife (N=80) caregivers. Table 3 describes the sample means of the total group of caregivers (N=118) in reference to each specific caregiving task. Table 4 summarizes mean levels of distress experienced by husbands and wives related to each specific type of caregiver task (see Appendix A for a list of the 12 caregiving tasks). Differences among the two groups of caregivers are discussed.

As summarized in Table 2, (response categories are combined for the purpose of reporting above data. Sm. amt. = Little/none + sm. amt., Mod. amt. = mod. amt., Large amt. = Quite a bit + a Great Deal) variables associated with time and caregiving tasks are relatively evenly distributed across tasks and time associated with caregiving tasks. Caregivers were engaged most frequently with activities associated with IADL, particularly household tasks where a greater percent of husbands indicated they spent a large amount of time with this activity as compared to wives. Caregivers also indicated they spent large amounts of time with running errands (wives =52%, husbands =53%), and assisting with finances, where a greater percentage of wives than husbands indicated they spent a large amount of time with this task. Nearly the same percentage of husbands and wives (42% and 46% respectively) indicated they spent a large amount of time assisting with personal care activities. In contrast, caregivers were engaged the least amount of time with activities associated with health care tasks. A greater percentage of husbands as opposed to wives indicated they spent a small amount of time on medical/nursing treatments. Also of note, a large percentage of husbands and wives (59% and 77% respectively) indicated they spent small amounts of time assisting their spouse with walking.

As summarized in Table 3, mean time scores for husbands were higher for personal care assistance, assisting with walking, health care tasks, and coordinating resources. This data may be supported by data that indicates male spouse caregivers were caring for more cognitively impaired and ADL dependent care recipients. Mean time scores were higher for women with regard to assisting with transportation. Even though husbands had more impaired care recipients, wives report higher time scores related to management of behavior problems. Both men and women reported equal amounts of time spent providing their spouse with emotional support.

No significant differences were found among the mean time scores (time spent on caregiving tasks) for each specific task between the two groups, except for time spent assisting with transportation ($p < .05$). Wives rated the time spent assisting with transportation higher in each response category compared with husbands. While sample mean time scores were higher for men in assistance with personal care, walking/getting out of bed, household tasks, medical/nursing treatments, monitoring and reporting symptoms, planning activities, and coordinating resources, differences between the two group means are not statistically significant. Likewise, sample mean time scores were higher for woman with assistance with finances, running errands, and behavior problems, differences between group means were not significant. Mean time scores of husband and wives for time spent providing emotional support to their spouse with dementia were equal. Because it is not possible to sort out those caregivers who did not spend at least a little amount of time on a particular caregiving task, it cannot be concluded that all caregivers spend at least some amount of time on any given task.

Table 2 - Time Spent with Caregiving Tasks-Comparison of Husbands and Wives

	Small Amount	Moderate Amount	Large Amount
ADL Personal Care	Husbands 7 (19%) Wives 29 (36%)	Husbands 15 (39%) Wives 14 (18%)	Husbands 16 (42%) Wives 37 (46%)
Assist Walk	Husbands 22 (59%) Wives 61 (77%)	Husbands 10 (27%) Wives 7 (9%)	Husbands 5 (14%) Wives 12 (14%)
IADL Transportation	Husbands 19 (51%) Wives 26 (33%)	Husbands 9 (24%) Wives 16 (20%)	Husbands 9 (25%) Wives 37 (47%)
Finances	Husbands 14 (37%) Wives 21 (26%)	Husbands 9 (23%) Wives 14 (18%)	Husbands 15 (40%) Wives 45 (56%)
HH Tasks	Husbands 3 (8%) Wives 16 (20%)	Husbands 10 (26%) Wives 18 (22%)	Husbands 25 (66%) Wives 46 (58%)
Errands	Husbands 5 (13%) Wives 10 (13%)	Husbands 13 (34%) Wives 28 (35%)	Husbands 20 (53%) Wives 42 (52%)
Health Care Med/Nursing	Husbands 22 (58%) Wives 43 (54%)	Husbands 9 (24%) Wives 21 (26%)	Husbands 7 (18%) Wives 16 (20%)
Monitor S/S	Husbands 21 (56%) Wives 49 (62%)	Husbands 10 (26%) Wives 17 (22%)	Husbands 7 (19%) Wives 13 (16%)
Behavior Mgmt. Emotional Support	Husbands 9 (24%) Wives 19 (25%)	Husbands 14 (37%) Wives 30 (38%)	Husbands 15 (39%) Wives 29 (37%)
Behavior Problems	Husbands 13 (34%) Wives 14 (18%)	Husbands 12 (32%) Wives 34 (43%)	Husbands 13 (34%) Wives 31 (40%)
Social Recreation Plan Activities	Husbands 14 (37%) Wives 25 (32%)	Husbands 7 (18%) Wives 31 (39%)	Husbands 17 (45%) Wives 24 (29%)
Coordinate Res.	Husbands 16 (43%) Wives 29 (37%)	Husbands 6 (16%) Wives 21 (27%)	Husbands 16 (42%) Wives 29 (37%)

Table 3 - Caregiver time spent with Caregiving Tasks-Total Sample

Caregiver Task	Total Sample N=118 (Mean)	Husbands N=38 (Mean)	Wives N=80 (Mean)	2-tail sig
ADL				
Personal Care	3.24	3.39	3.16	p=.36
Assist Walk	2.09	2.32	1.97	p=.19
IADL				
Transportation	2.97	2.45	3.20	p=.01
Finances	3.72	3.18	3.51	p=.22
HH Tasks	3.04	3.94	3.61	p=.18
Errands	3.23	3.57	3.62	p=.83
Health Care				
Med/Nursing	2.57	2.60	2.55	p=.81
Monitor S/S	2.32	2.42	2.26	p=.51
Behavior Mgmt.				
Emotional Support	3.16	3.15	3.15	p=.98
Behavior Problems	3.23	3.00	3.34	p=.15
Social Recreation				
Plan Activities	3.04	3.10	3.01	p=.71
Coordinate Res.	3.01	3.10	2.96	p=.60

Table 4 - Distress Associated with Caregiver Tasks-Total Sample

Caregiver Task	Total Sample N=118 (Mean)	Husbands N=38 (Mean)	Wives N=80 (Mean)	2-tail sig
ADL				
Personal Care	2.53	2.57	2.51	p=.79
Assist Walk	1.78	1.78	1.77	p=.95
IADL				
Transportation	1.86	1.64	1.96	p=.17
Finances	2.44	2.15	2.58	p=.11
HH Tasks	2.48	2.52	2.45	p=.75
Errands	2.27	2.07	2.36	p=.24
Health Care				
Med/Nursing	1.91	1.89	1.91	p=.94
Monitor S/S	1.97	1.94	1.98	p=.86
Behavior Mgmt.				
Emotional Support	2.49	2.57	2.44	p=.59
Behavior Problems	3.04	2.84	3.14	p=.23
Social Recreation				
Plan Activities	2.38	2.44	2.35	p=.70
Coordinate Res.	2.38	2.10	2.51	p=.09

Overall, individual analysis of each of the 12 caregiving tasks outlined in the questionnaire reveals no significant differences in distress scores among husband and wife caregivers on any of the 12 tasks. Mean distress scores for both the combined group and husband and wife groups show less than moderate amounts of distress associated with each caregiving task with the exception of assistance with behavior problems, which indicates that there are moderate amounts of distress associated with this task for the combined group, as well as wives separately.

Differences in Overall Distress Among Men and Women

Reliability analysis of distress scores demonstrated that distress in one task area is highly correlated with distress in other task areas. A mean inter-item correlation of .42 and a Cronbach's alpha of .90 appear to indicate that distress is a general psychological phenomenon that is not confined to particular tasks. Thus, the 12 distress scores were combined into a single score for further analysis. As the data in Table 5 show, the mean distress scores combined across all 12 tasks is 2.29. The associated SD is .83; skewness .69; minimum value 1.00; maximum value 4.75. The t-test comparing the overall distress scores between the male and female spouse caregivers demonstrates no significant differences between them, $p>.05$ (see Table 5).

Table 5 - t-tests of Independent Samples for Mean/Overall Distress

Variable	Combined	Husbands	Wives	2-tail sig.
Distress	2.29	2.21	2.31	.53

Analysis of Effects of Extraneous Variables

Because time spent on a particular caregiving task is a possible confounding influence on distress, a correlational analysis was used to evaluate the relationship between time spent with each task and distress. The analysis revealed a strong relationship between distress with each task and time spent with each task.

To simplify analysis, a reliability analysis was also performed on the time variables to see if spouse time spent on caregiving activities varies consistently across all 12 task domains. Again, a Cronbach's alpha of .83 and a inter- item correlation of .30 justifies treating caregiver involvement as a single measure indicating consistent variation in care involvement across all task domains with a mean value of 3.03, SD .75; skewness= .198, minimum value=1.00, maximum value=4.92

As already established, the two groups of caregivers differ with respect to age, patient ADL dependency, and cognitive disability. Therefore, the possible influence of these variables on the dependent variable of distress was considered. In addition, because of the strong relationship between time spent caregiving and distress, time was considered to be a possible confounder as well.

Multivariate analysis (ANCOVA) was used to control for these variables. Results indicate that time spent on caregiving tasks had the greatest influence on caregiver distress accounting for 29% of the variation in distress scores. Other significant factors influencing caregiver distress are the care recipient's cognitive limitations (accounting for 5% of the variation in distress scores) and caregiver age (2.2% of variation in distress scores). No other variables appear to influence spouse caregiver distress. In particular, as the data in Table 6 show, caregiver gender does not affect spouse caregiver distress. Even after adjusting for the effects of patient disabilities (cognitive and physical), caregiver age and caregiver time involvement in care, no differences in male and female distress scores were found. If anything, the adjusted means suggest a lower distress score among male caregivers.

Table 6 - Unadjusted and Adjusted Means
(Adjusted for patient disability, caregiver age, and caregiver time spent in care)

	Unadjusted Mean	Adjusted Mean
Men	2.22	2.13
Women	2.32	2.37
p value	.538	.094

In conclusion, no gender differences could be demonstrated among husband and wife caregivers with regard to distress associated with specific tasks or overall distress associated with specific tasks. No significant differences among the two groups could be found regarding time spent with caregiver tasks except with transportation. However, time involved with each task was significantly correlated with distress with each task and is more strongly related to distress than gender itself.

Discussion

Methodological Limitations

The reader should exercise caution when attempting to generalize these research findings to the clinical setting. The small sample size and lack of random selection of study participants limits the usefulness of study results.

Homogeneity among sample subjects limits generalizability of findings to only those with similar characteristics and who meet similar inclusion criteria only. A larger sample would have allowed for broader use of and interpretation of study findings.

The version of the caregiver activity scale as adapted for this study had not been previously tested in the literature. Currently, there is no published reliability or validity information available on this version of the scale. Lack of this information may limit interpretation of study findings.

The sample of caregivers who were used for inclusion in this study were drawn from various community based agencies in south west Michigan. It is possible that caregivers connected with these types of agencies may be receiving support services that ease a general sense of burden, allowing caregivers to be more tolerant of the demands associated with caregiving tasks. In turn, this may influence distress scores among this group. Additionally, perhaps caregivers who are connected with helping agencies may be more independent in help-seeking behaviors, know where and how to access help, and, therefore, have better coping skills and lower distress scores. This study did not measure pre-existing coping skills or community based support services among this group of spouse caregivers.

All possible response categories were included in data analysis for both distress and time spent on caregiving tasks ranging from little to none (=1) to a great deal (=5). There may be some respondents included who have no involvement in particular tasks. This, in turn, may depress the distress scores associated with these tasks. In addition, data representing those caregivers who report no time spent with a particular activity may skew the mean scores associated with each task, and inadequately represent study findings.

While gender did not prove to influence differences in distress levels between husband and wife caregivers with respect to caregiving tasks in this study, larger samples of a more heterogeneous population may demonstrate different findings.

Interpretation of Findings

Findings from this study indicate no significant differences between male and female spouse caregivers with respect to distress associated with specific or groups of caregiving tasks. Findings would appear to support the work of those researchers who believe that gender differences among spouse caregivers are generally not significant or lacking all together. Miller and Cafasso (1992) conclude that too much emphasis is placed on non-significant findings and not enough on findings that suggest the presence of no differences. It is noted, however, that even though data from this study did not support gendered differences among spouse caregivers with respect to distress associated with caregiving tasks, one cannot rule out the possibility that gender differences may be more obvious among other caregiver-care recipient dyads. For example, adult child caregivers may find certain tasks more distressful than others, depending on the gender of the caregiver and the relationship they have to the care recipient. Therefore, the influence of gender or caregiver reactions may be confounded by the caregiver-care recipient relationship.

In light of the literature that says women are more distressed than men regardless of their participation in caregiving situations, the women and men in this sample had no differences between them with respect to distress and associated caregiving tasks. It may be that women do not have increasing levels of distress when engaged in caregiving, but maintain their general higher levels of distress associated with previous roles. Additionally, men may indeed have an increase in distress associated with caregiving, putting them on equal ground with the women. If this is true, then one would conclude that men have more distress caused by activities of caregiving than women.

It would appear that analysis of specific caregiving activities one by one does not prove to generate different findings from analysis of caregiver task domains. Therefore, the literature that discusses caregiver distress based on groups of caregiving tasks appears to be supported by results of this study.

No significant differences were found among the two groups of caregivers with respect to time spent with each caregiving task or groups of tasks, with exception of transportation where wife caregivers were found to spend more time than husbands assisting the patient with this particular activity. This finding is in conflict with literature by other researchers that report the male as the primary provider of this type of caregiving activity (Young & Kahana, 1989; Barusch & Spaid, 1989). Findings are in conflict with those who support the notion that caregivers participate in gender specific tasks (Stoller, 1990). One might assume that men would help more with this task particularly if the wife does not drive or is unable to assist her husband who may be more physically difficult to manage based on his size. However, it is noted that the male caregivers in this study sample had more dependent and cognitively impaired spouses than female participants. Therefore, the male caregivers may have been unable to transport their spouse outside of the home due to their spouse's level of illness. This type of situation would influence time spent by husbands on transportation as a caregiving activity.

Mean distress scores related to individual caregiving activities were low to moderate for the combined sample and for the individual groups of spouse caregivers. Differences among the two groups of caregivers were not significant. Results indicate that participation in the caregiving activities included in this study was no more than moderately distressful for this population of caregivers, and that gender was not a significant influence on distress experienced. Since results support findings of other researchers who found similar distress levels in relation to caregiving activities (Farran et al., 1993), perhaps caregiving tasks do not necessarily produce significantly high distress levels. One cannot rule out, however, that other aspects of caregiving may produce high levels of distress among spouse caregivers. Mean time scores indicate spouse caregivers spending only small to moderate amounts of time on caregiving activities. Again, no significant differences were found between husband and wife caregivers with respect to time spent on caregiving tasks. This finding is in conflict with some research that finds men and women participating in differing types of care reflecting the cultural division of labor based on sex (Stoller, 1990).

The caregiving model developed by Given, Collins, and Given (1988) depicts the complex interrelationship between patient/caregiver characteristics, type and quality of prior caregiver-patient relationships, caregiver reactions, impact on caregiver physical and mental health, and the maintenance of the caregiving role. While the caregiver characteristic of gender did not influence distress associated with caregiving tasks in this study, the possibility that gender may influence other aspects of the caregiving experience still exists. The model allows for the possible positive caregiver reactions in response to caregiving. Low to moderate amounts of distress with caregiving activities may lead to a positive, or at least neutral, effect on caregiver well being, and may in turn encourage maintenance of the caregiving role.

The caregiving model is broad enough to allow for the wide range of patient/caregiver characteristics that extend beyond gender. As suggested by study findings, time spent on caregiving tasks by the caregiver may have an influence on distress experienced with caregiving tasks. The model supports the conception that the interaction of time and caregiver activities may impact the caregivers ability to maintain the caregiving role because of the influence of time involved with caregiver tasks, on caregiver reactions.

Study findings also suggest that patient characteristics such as cognitive dysfunction and ADL dependency needs are correlated with distress experienced by the caregiver. Again, the model is useful for allowing the influence of patient characteristics beyond gender on the caregivers reaction to caregiving. As described by the model, caregiver health is impacted by the caregivers response to caregiving, demonstrating the importance of caregiver reaction to caregiver well-being. While study findings did not indicate distress levels that were relatively high with respect to individual or groups of caregiving tasks, the model would indicate some degree of impact on caregiver health. The model does not demonstrate the degree of influence on caregiver health by varying degrees of caregiver reactions, but merely that an interaction between the two concepts occur.

Implications for Advanced Nursing Practice and Primary Care

Because issues associated with dementia have become a major public health issue, the CNS will need to define her/his role within the health care delivery system in dealing with these issues. The CNS specializing in gerontology is in a key position to influence the care of dementia patients and the health and well being of their caregivers.

Recognizing the presence or absence of gender differences may assist the CNS in developing intervention strategies that allow for the differing needs of male and female spouse caregivers of dementia patients. Although there were no significant gender differences among spouse caregivers in this sample with respect to distress associated with each caregiving task, findings did indicate that certain tasks may cause moderate distress for both the husband and wife caregiver. Although further research with a larger sample would prove more conclusive to the general population, the CNS can use the information from this study to increase her/his awareness that participation in caregiving tasks may influence distress levels of both gender, and that time involved in each task may have more of an influence on distress than gender itself. Based on this information, the CNS may want to ask questions of the caregiver that would provide information about the distress and time associated with caregiving activities. For example, it may prove useful to inquire as to which caregiving tasks the caregiver engages, and how much time the caregiver perceives he/she spends on particular tasks. Caregivers may be asked to fill in a pie-shaped diagram indicating amounts of time (by areas of the pie) spent in task areas. This information would help the CNS discover which task areas may be associated with higher amounts of distress. Intervention strategies aimed at decreasing time involved with specific tasks may help decrease distress levels and improve the caregiver's response to caregiving.

Integration of the concepts of the caregiving model used for the purpose of discussion of this study, into a comprehensive nursing assessment would allow for the nurse to more thoroughly evaluate the various aspects of the caregiving situation, and the potential impact of various variables on caregiver reactions to caregiving. The nurse must take into account that a variety of caregiving factors may be working together in such a way as to influence caregiver reactions. Using the model as a guide for assessing many of the possible aspects that influence caregiving, the CNS can assess the potential for maintenance of the caregiving role based on the variables that are interacting with the caregiving environment. Counseling strategies may be needed to help balance the level of interaction between variables in such a way as to enhance positive coping skills among caregivers that may stimulate positive caregiving experiences.

According to Stetler and Marram (1978), the nurse needs to evaluate a study's findings for appropriateness of application of findings to clinical practice. Similarity of characteristics of the sample and the study's environment, to the population with which the nurse works, and environment in which the nurse practices are important in order to evaluate applicability to practice. It is also necessary for the nurse to decide whether she/he needs to change her/his practice based on the effectiveness of current intervention strategies. In addition, it is helpful to evaluate the legal and ethical risks and resources involved with application of study findings to a clinical practice situation, that is, how feasible is it to implement study findings. Based on this evaluation, the nurse may choose not to apply findings to her/his practice, or to apply findings either directly or cognitively. Because of the limitations of this study, the CNS may choose to use the information put forth in this thesis as a means for increasing information in her/his "theoretical approach to nursing" (Stetler & Marram, 1978. p. 563). This cognitive application would be appropriate in this study situation as the CNS uses this information to heighten her/his appreciation for a given caregiving situation (Stetler & Marram, 1978). Direct application of study results may not be possible due to limitations of the study findings previously discussed.

Study findings indicate that men and women both assist with the same types of caregiving activities, mean time scores were similar between the two groups of caregivers, except with regard to time spent with transportation where women seemed to spend more time than men with this task. Based on this information, the CNS may reconsider any past gender bias that she/he has with regard to caregiving activities and be aware that society's image that caregiving is largely a female endeavor (Miller & Cafasso, 1992), may not hold true in all cases. The CNS can educate others in this area and promote a more realistic view of the male role in caregiving situations.

Recommendations for Future Research

Does the concept gender differences in distress associated with caregiving tasks need further investigation? A vast amount of literature is available on burden, stress and distress associated with caregiving as well as gender and the impact gender has on caregiver reactions. Based on the results of this study, and the work of many researchers, it appears that the literature has adequately dealt with these issues. However, little has been done to evaluate the impact of caregiver reactions on the care recipient. This author proposes that information about care outcomes based on caregiving demands are more important than any gender differences that may exist among caregivers. Several questions remain unanswered. Are patients with dementia well cared for by their spouse caregivers and what variables influence good care? In what way do care recipients respond to caregiver reactions, and in what way do caregiver reactions such as distress influence certain patient outcomes? This author proposes further research is necessary to adequately respond to these questions.

Using larger samples, it may prove interesting to investigate the connection between current care recipient impairment and current caregiver distress to determine whether perceived distress levels are actually reflective of current caregiving demands or if they reflect more long term, accumulated care demands.

Research needs to address the caregiver's desire to participate in the caregiving situation, and the implications this has on the caregiving experience. Males may have an easier time avoiding the caregiving role, therefore, male caregivers who have accepted the role may be those that want to participate in caregiving. Perhaps self selection acts as an influence on psychological reactions and may explain any gender differences that do exist among spouse caregivers with respect to various aspects of caregiving.

Participants in this study were predominantly white, and other race populations and ethnic backgrounds were not adequately represented. Further research for gender differences with specific caregiving tasks may prove useful for describing other types of ethnic /race caregivers.

Other variables identified in this study as possible confounders for distress, such as time spent on caregiving activities, caregiver age, and care-recipient disability, may have a more significant role in influencing caregiver distress than gender, and may be worthy of further investigation.

Although dramatic conclusions cannot be drawn from study results with this sample of caregivers, findings do support the need for further research in other aspects of dementia caregiving among spouse caregivers and identifies the need to address the effectiveness of current nursing approaches.

APPENDICES

APPENDIX A

APPENDIX A

Caregiver Activities Scale

For each of the following caregiving activities, please tell me:

-- how much time you spend performing the activity.
-- how much distress, effort, or difficultly the activity causes you.

We are aware that some things you may spend a great deal of time doing may not be bothersome for you. Yet, other things you only do occasionally may be quite distressing for you. So, for each activity we would like you to indicate both the amount of time and the distress it causes you. Place a check mark in front of the answer which best describes the amount of time you spend in each activity, and the amount of distress the activity causes you.

1. Medical or nursing treatments (giving medications, changing dressings, skin care, exercises, etc.):

Time (check one)	Distress (check one)
__ A great deal	__ A great deal
__ Quite a lot	__ Quite a lot
__ A moderate amount	__ A moderate amount
__ A small amount	__ A small amount
__ Little or none	__ Little or none

2. Personal care (bathing, toileting, feeding, getting dressed, etc.):

Time (check one)	Distress (check one)
__ A great deal	__ A great deal
__ Quite a lot	__ Quite a lot
__ A moderate amount	__ A moderate amount
__ A small amount	__ A small amount
__ Little or none	__ Little or none

3. Assistance with walking, getting in and out of bed, etc.:

Time (check one)	Distress (check one)
__ A great deal	__ A great deal
__ Quite a lot	__ Quite a lot

__ A moderate amount	__ A moderate amount
__ A small amount	__ A small amount
__ Little or none	__ Little or none

4. Emotional support (for the patient and/or others):

Time (check one)	Distress (check one)
__ A great deal	__ A great deal
__ Quite a lot	__ Quite a lot
__ A moderate amount	__ A moderate amount
__ A small amount	__ A small amount
__ Little or none	__ Little or none

5. Monitoring and reporting symptoms and progress:

Time (check one)	Distress (check one)
__ A great deal	__ A great deal
__ Quite a lot	__ Quite a lot
__ A moderate amount	__ A moderate amount
__ A small amount	__ A small amount
__ Little or none	__ Little or none

6. Providing transportation:

Time (check one)	Distress (check one)
__ A great deal	__ A great deal
__ Quite a lot	__ Quite a lot
__ A moderate amount	__ A moderate amount
__ A small amount	__ A small amount
__ Little or none	__ Little or none

7. Managing finances, bills, and insurance forms related to this illness:

Time (check one)	Distress (check one)
__ A great deal	__ A great deal
__ Quite a lot	__ Quite a lot
__ A moderate amount	__ A moderate amount
__ A small amount	__ A small amount
__ Little or none	__ Little or none

8. Additional household tasks (laundry, cooking, cleaning, etc.):

Time (check one)	Distress (check one)
__ A great deal	__ A great deal
__ Quite a lot	__ Quite a lot
__ A moderate amount	__ A moderate amount
__ A small amount	__ A small amount
__ Little or none	__ Little or none

9. Additional tasks outside the home (shopping for food and clothes, going to the bank, running errands);

Time (check one)	Distress (check one)
__ A great deal	__ A great deal
__ Quite a lot	__ Quite a lot
__ A moderate amount	__ A moderate amount
__ A small amount	__ A small amount
__ Little or none	__ Little or none

10. Structuring/planning activities for your relative (recreation, meals, rest, things for your relative to do, etc.):

Time (check one)	Distress (check one)
__ A great deal	__ A great deal
__ Quite a lot	__ Quite a lot
__ A moderate amount	__ A moderate amount
__ A small amount	__ A small amount
__ Little or none	__ Little or none

11. Managing behavior problems (moodiness, irritability, confusion, memory loss):

Time (check one)	Distress (check one)
__ A great deal	__ A great deal
__ Quite a lot	__ Quite a lot
__ A moderate amount	__ A moderate amount
__ A small amount	__ A small amount
__ Little or none	__ Little or none

12. Coordinating, arranging, and managing services and resources (scheduling appointments, arranging transportation, locating equipment and services, finding outside help):

Time (check one)	**Distress** (check one)
__ **A great deal**	__ **A great deal**
__ **Quite a lot**	__ **Quite a lot**
__ **A moderate amount**	__ **A moderate amount**
__ **A small amount**	__ **A small amount**
__ **Little or none**	__ **Little or none**

APPENDIX B

Appendix B

MICHIGAN STATE
UNIVERSITY

OFFICE OF
RESEARCH
AND
GRADUATE
STUDIES

University Committee on
Research Involving
Human Subjects
(UCRIHS)

Michigan State University
232 Administration Building
East Lansing, Michigan
48824-1046

517/355-2180
FAX: 517/432-1171

March 13, 1996

TO: Kathy Reid
5050 Shady Creek Dr.
Muskegon, MI 49441

RE: IRB#: 96-118
TITLE: GENDER DIFFERENCES AMONG SPOUSE CAREGIVERS OF PATIENTS WITH DEMENTIA IN DISTRESS ASSOCIATED WITH CAREGIVING TASKS
REVISION REQUESTED: N/A
CATEGORY: 2-H
APPROVAL DATE: 03/13/96

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 and any revisions listed above.

RENEWAL: 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 use the green renewal form (enclosed with the original approval letter or when a project is renewed) to seek updated certification. 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.

REVISIONS: UCRIHS must review any changes in procedures involving human subjects, prior to initiation of the change. If this is done at the time of renewal, please use the green renewal form. To revise an approved protocol at any other time during the year, send your written request to the UCRIHS Chair, requesting revised approval and referencing the project's IRB # and title. Include in your request a description of the change and any revised instruments, consent forms or advertisements that are applicable.

PROBLEMS/ CHANGES: Should either of the following arise during the course of the work, investigators must notify UCRIHS promptly: (1) problems (unexpected side effects, complaints, etc.) involving human subjects or (2) changes in the research environment or new information indicating greater risk to the human subjects than existed when the protocol was previously reviewed and approved.

If we can be of any future help, please do not hesitate to contact us at (517)355-2180 or FAX (517)432-1171.

Sincerely,

David E. Wright

David E. Wright, Ph.D.
UCRIHS Chair

DEW:bed

cc: Clare Collins

APPENDIX C

APPENDIX C

ADL Dependency Scale

1. 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 your relative always wears bed clothing during the day, answer "NEVER DRESSED". Select the category that best describes your relative's level of functioning for DRESSING.

My relative...

__ IS INDEPENDENT -- (does not need help of another person in any part of this activity.)

__ 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.) RELATIVE PARTICIPATES.

__ NEEDS TOTAL PHYSICAL HELP -- (needs another person to carry out this activity.) RELATIVE DOES NOT PARTICIPATE.

__ NEVER DRESSED

2. EATING: This category includes all types of food and liquid taken by mouth.

> [Interviewer: Includes all types of presentation used -- tray, finger foods, etc.; client does not need to use utensils. Does not include selection or preparation of food.]

My relative...

__ IS INDEPENDENT -- (does not need help of another person in any part of this activity.)

__ 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.) RELATIVE PARTICIPATES.

__ NEEDS TOTAL PHYSICAL HELP -- (needs another person to carry out this activity.) RELATIVE DOES NOT PARTICIPATE.

3. GROOMING: This category includes the following activities: combing or brushing hair, shaving, brushing teeth and cleaning dentures, cleaning and clipping fingernails. Select the category that best describes your relative's level of functioning for grooming.

My relative...

__ IS INDEPENDENT -- (does not need help of another person in any part of this activity.)

__ 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.) RELATIVE PARTICIPATES.

__ NEEDS TOTAL PHYSICAL HELP -- (needs another person to carry out this activity.) RELATIVE DOES NOT PARTICIPATE.

4. 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. Does not include washing of head or drying hair. Does not include dressing or undressing. Select the response that best describes your relative's level of functioning for bathing.

My relative...

__ IS INDEPENDENT -- (does not need help of another person in any part of this activity.)

__ 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.) RELATIVE PARTICIPATES.

__ NEEDS TOTAL PHYSICAL HELP -- (needs another person to carry out this activity.) RELATIVE DOES NOT PARTICIPATE.

5. WALKING INSIDE THE HOUSE: This category includes all upright movement on foot over the floor inside the house. MUST MOVE AT LEAST

FIVE FEET. May use cane, walker, crutches, or handrail. Select the response that best describes your relative's level of functioning for walking.

My relative...

__ IS INDEPENDENT -- (does not need help of another person in any part of this activity.)

__ 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.) RELATIVE PARTICIPATES.

__ NEEDS TOTAL PHYSICAL HELP -- (needs another person to carry out this activity.) RELATIVE DOES NOT PARTICIPATE.

__ UNABLE TO WALK -- (will not bear weight.)

6. TOILETING: This category includes all those behaviors associated with bowel/bladder emptying: getting to and from toilet (or use of toileting equipment such as bedpan), removal/adjustment of clothing, positioning on toilet, cleaning of body parts, replacement of clothing. Select the response that best describes your relative's level of functioning for toileting.

My relative...

__ IS INDEPENDENT -- (does not need help of another person in any part of this activity.)

__ 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.) RELATIVE PARTICIPATES.

__ NEEDS TOTAL PHYSICAL HELP -- (needs another person to carry out this activity.) RELATIVE DOES NOT PARTICIPATE.

__ DEVICE -- (catheter or ostomy is used.)

7. TRANSFERRING: This category includes movement to and from bed, to chair or wheelchair, or set on toilet or commode. Devices, bars, and other mechanical aids may be used. Select the response that best describes the relative's level of independence.

My relative...

__ **IS INDEPENDENT** -- (does not need help of another person in any part of this activity.)

__ **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.) RELATIVE PARTICIPATES.

__ **NEEDS TOTAL PHYSICAL HELP** -- (needs another person to carry out this activity.) RELATIVE DOES NOT PARTICIPATE.

__ **REMAINS BEDFAST**

8. BED MOBILITY: This category includes movement to avoid pressure sores. May include sitting up in bed or on edge of bed. Devices, bars, trapezes, and other mechanical aids may be used. Select the response that best describes your relative's level of functioning for bed mobility.

My relative...

__ **IS INDEPENDENT** -- (does not need help of another person in any part of this activity.)

__ **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.) RELATIVE PARTICIPATES.

__ **NEEDS TOTAL PHYSICAL HELP** -- (needs another person to carry out this activity.) RELATIVE DOES NOT PARTICIPATE.

APPENDIX D

APPENDIX D

Cognitive Functioning Scale

These next questions are about your relative's mental functioning and need for supervision. For each of the following, please select the answer that best describes your relative's functioning.

1. ORIENTATION: Identify the individual's orientation to person, place, and time as it relates to their ability to function independently.

__ Oriented to person, place, and time: Knows who self and others are in daily contact; knows where he/she is; knows day, month and year.

__ Occasionally disoriented to person, place, or time, but is sufficiently oriented to function independently if in familiar surroundings.

__ Frequently disoriented.

__ Always disoriented.

2. JUDGMENT: Identify the individual's ability to use judgment, make decisions, and conduct activities that affect their ability to function independently.

__ Judgment is good. Makes appropriate decisions (e.g., choosing clothes).

__ Judgment is occasionally poor; needs monitoring and guidance in decision making.

__ Judgment is frequently poor; needs protection and supervision because person makes unsafe or inappropriate decisions (e.g., where and when to smoke).

__ Judgment is always poor; cannot make any appropriate decisions for self.

3. MEMORY: Identify the individual's ability to remember and use information appropriately.

__ Does not have difficulty remembering and using information. Does not require directions or reminding from others.

__ Has minimal difficulty remembering and using information. Requires occasional direction and reminding from others. May be able to follow written instructions.

__ Has difficulty remembering and using information. Requires frequent direction and reminding from others. Cannot follow written instructions.

__ Cannot remember or use information. Requires continual verbal reminding.

4. WANDERING: Identify individual's tendency to wander away from home. Wandering is leaving home without purpose or with inappropriate purpose and without a relationship to needs or safety.

__ Does not wander and can walk.

__ Does not wander; is chairbound or bedbound.

__ Wanders outside but is not a danger to self (or would wander outside if not prevented from doing so by you or others).

__ Wanders outside and is a danger to self (or would wander outside and be a danger to self if not prevented from doing so by you or others).

5. AWARENESS OF OWN NEEDS: Identify the degree to which the individual understands their needs relating to health, and safety.

__ Understands own health and safety needs.

__ Sometimes does not understand health and safety needs.

__ Usually does not understand health and safety needs.

__ Does not understand own health and safety needs.

6. NIGHT NEEDS: Identify the individual's need for assistance during the night.

__ Does not require care or supervision from another person during the night.

__ Requires minimal care and supervision.

__ Requires substantial care and supervision. Provider cannot usually get at least five hours of sleep during an eight-hour period.

__ Requires constant care and supervision.

7. GENERAL SUPERVISION: How much overall supervision does your relative require. Choose the response which best describes your relative's situation.

__ Can be left alone all day.

__ Can be left alone for periods of more than two hours during the day.

__ Can be left alone for brief periods of less than two hours during the day.

__ Must be watched constantly if awake.

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