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# Relationship Between Level of Burden in Family Caregivers and Life Satisfaction in Homebound Elders

Lorraine G. Hamm

A Thesis

Submitted in partial fulfillment of the requirements for the Degree of Master of Science in Nursing in the Division of Nursing Mississippi University for Women

Columbus, Mississippi

August, 1990

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# Relationship Between Level of Burden in Family Caregivers and Life Satisfaction in Homebound Elders

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#### Abstract

As the number of homebound elders in America increases, stresses on family caregivers for the group may develop. The purpose of this study was to examine the relationship between level of burden in family caregivers and life satisfaction in homebound elders. Roy's Adaptation Model was used to guide this descriptive correlational investigation.

The sample consisted of 53 family caregiver/homebound elder dyads and was drawn from among clients of a home health agency in rural northwest Alabama. Participants were interviewed in their homes during routine nursing visits. The Burden Scale was used to assess the level of burden in family caregivers living in residence with homebound elders. The Life Satisfaction Index-Z Scale was used to ascertain the level of life satisfaction in homebound elders.

Pearson correlation procedures revealed an inverse relationship between level of burden in family caregivers and life satisfaction in homebound elders at the .05 level of significance. A dependent <u>t</u> test indicated that subjective burden was significantly greater than objective burden.

Findings from this study implied that assessing the dynamics of the interpersonal relationship between family caregivers and homebound elders is an important consideration for nurses in primary care. Recommendations for future research included the conduction of studies specific to the development of nursing interventions to relieve caregiver burden and enhance life satisfaction in homebound elders.

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#### Chapter I

#### The Research Problem

America is getting older. In the past 20 years the elderly population in the United States has grown twice as fast as the general population (Osterkamp, 1988). In 1984, the Special Committee on Aging predicted that by the year 2000 nearly 20% of the American people will be over the age of 65 years (Perkins, 1987).

As life expectancy increases there will be a rise in the incidence of chronic illness and functional impairment in this older group resulting in more elders becoming homebound. Thus, the need for physical, financial, social, and emotional support for elders also will increase.

Concomitant with the increased need for support comes expected decreases in government programs for the aged, leading to shorter hospital stays and fewer nursing home admissions. The value of home care emerges as a significant factor in the consideration of the future of health care for elders.

Family members are already an integral part of the health care system for homebound elders. Family members are now providing more than 80% of the home health care needed by elders (American Association of Retired Persons [AARP],

1988; Bunting, 1989; Heagarty, Dunn, & Watson, 1988). As the demand on family members intensifies, experiences of physical and emotional strain, most often labeled "caregiver burden," frequently occur.

While researchers agree that a perceived sense of burden adversely affects both members of the caregiver/carereceiver pairs, the dyadic relationships between family caregivers and homebound elders in these situations rarely have been scrutinized (Bunting, 1989; Perkins, 1987; Phillips & Rempusheski, 1986). With the increasing incidence of families caring for elders in a home setting, it is important that the relationships which exist between caregivers and homebound elders be explored.

#### Purpose of the Study

The purpose of this study was to examine the relationship between level of burden in family caregivers and life satisfaction in homebound elders. This information is useful to nurses providing home care who are concerned with the need to gain greater insight into the causative factors of burden. Interventions to alleviate burden and promote a sense of satisfaction in elders then can be planned.

# Background and Significance of the Study

Professional organizations, advocacy groups, and popular media are responding to the growth in the number of persons over age 65 (Osterkamp, 1988). Senior citizen centers, respite centers, and transportation modes for older people are becoming increasingly available for well or mildly impaired elders. In Congress, the push for higher reimbursements for hospital and nursing home stays for ill elders is an issue of national attention (Heagarty et al., 1988).

Still there remains a population of elders "in the middle": the homebound elders. Homebound elders neither require acute care nor are able to utilize community resources outside the home. However, because of an increasing functional impairment, or diminution of physical and emotional capacities, these elders are unable to maintain residence without the assistance of others (Federal Council on Aging, 1978).

While about 5% of elders aged 65-74 require this personal assistance, approximately 33% over that age group need help because of their homebound status (Osterkamp, 1988). An estimated 7 million older Americans need some assistance from other persons with activities ranging from intensive personal care to household maintenance and shopping (AARP, 1988).

The "other persons" are usually family members, or friends who act as surrogate family. Surveys consistently reveal that about 75% of family caregivers are women, and that the mean age of these women is about 50 years (AARP, 1988; Osterkamp, 1988; Scharlach, 1987). The homebound elder's spouse is the most likely significant other to become the caregiver, followed by adult daughters, then daughters-in-law, sons, and other relatives or surrogates. Approximately three fourths of the caregivers live in the home with the care recipient or have the elder in their homes (Osterkamp, 1988).

Because of the decrease in the availability of formal caregiving, many family caregivers do not assume their duties by choice but are thrust into the role (Heagarty et al., 1988). In an extensive national survey conducted in 1988, only 18% of primary caregivers admitted that they chose the role because of a closer relationship than others with the care recipient. Thirty-three percent of caregivers of elders took on the role because they were the only family members who lived nearby, and 25% said they had no choice because no one else was available to provide the necessary care (AARP, 1988).

In light of these statistics, it is not surprising that most of the effects of caregiving are equated with a sense of burden. Montgomery and Borgotta (1985) explored two domains of family caregiver burden: objective and

subjective. Objective burden was associated with stressful concrete events experienced by family caregivers, such as assisting elders with activities of daily living.

Subjective burden, a more elusive concept, was described as stressful feelings and attitudes of family members about their experiences of caring for a homebound elder.

Klein (1989) recognized that the focus on caregiver's perceptions of burden, rather than the care recipient's condition and physical needs, clarified the picture of burden. In Klein's (1989) interpretation of burden, the caregiver's perceived responsibility for and relationship with the recipient determined the level of burden felt by the caregiver.

Troubled feelings in home care situations are not limited to caregivers. Elderly recipients of care also report feelings of depression, low morale, decreased life satisfaction, and interpersonal difficulties in relationships with family caregivers (Perkins, 1987). Stuifenbergen's (1987) review of literature on the impact of chronic illness on families revealed that though in general the ill relative was less likely than the family member to see the impaired role as creating difficulties in emotional relationships, the individual's perceptions of the family as adjusting to the situation were critical to adaptation to chronic illness (Stuifenbergen, 1987).

Phillips and Rempusheski (1986) recognized that past research emphasis was on the documentation of the existence of elder-caregiver relationships and the description of the types of services that families provide. By using a grounded theory approach to explain the dynamics of poor quality family caregiving, the researchers clearly illuminated the current lack of theoretical and empirical data describing the dynamics of elder-caregiver relationships (Phillips & Rempusheki, 1986). Perkins (1987) suggested that in their zeal to investigate the phenomenon of caregiver burden, nurse researchers have overlooked the elderly carereceivers and their perceptions in the dyadic caregiver/homebound elder relationship.

Examining dyadic relationships in home situations of families with elders has a number of implications for the geriatric nurse clinician. This study of the relationship between level of burden in family caregivers and life satisfaction in homebound elders contributes to nursing research, nursing theory, nursing practice, and nursing education.

Nursing research. Currently, there is limited research and empirical data on the interrelationships of family caregivers and homebound elders. A dearth of information regarding the impact of caregiver burden on the elder recipient also is evident. Findings from this study may redound upon knowledge regarding the occurrence of burden in

family caregivers and its relationship to life satisfaction in homebound elders.

Nursing theory. This study serves to advance the establishment of the Roy Adaptation Model for nursing as an appropriate tool for identifying and assessing behaviors and relationships between family caregivers and elders. In particular, identification of behaviors within the interdependence mode of the model enhance understanding of the receptive and contributive factions of interdependence. With the number of elders being cared for at home continuing to increase rapidly, the testing of conceptual models upon which to base interventions is greatly needed.

Nursing practice. Geriatric nurse clinicians at the primary site of the home have a unique opportunity to assess burden in family caregivers of homebound elders.

Recognition of the phenomenon of burden and its impact on the life satisfaction of the elder enables clinicians to begin to identify causative factors and develop interventions for nursing management of caregiver burden. In addition, important information about life satisfaction in homebound elders is provided toward nursing interventions to enhance that phenomenon.

Nursing education. As costs rise and the provision of health care moves away from the acute setting, more graduates of schools of nursing will be practicing in the home setting. Findings from this study may contribute to

the development of a nursing curriculum that includes a focus on family caregivers. The teaching of interventions specific to the alleviation of caregiver burden and the promotion of life satisfaction in elders are especially pertinent at the graduate level where geriatric nurse clinicians will be responsible for the management of homebound elders.

#### Statement of the Problem

Researchers suggest that the American population is growing older and that governmental resources for health care of elders are being consumed rapidly. Consequently, more elders will be cared for in the home by family members.

As the demands on family caregivers have been magnified, so has the focus of attention on the burden assumed by the group. Unfortunately, this emphasis has cast elders in a negative, dependent role with little attention given to the effect carereceiving is having on the elders' morale and sense of satisfaction with life (Perkins, 1987).

A major challenge for health care delivery in the 1990s is to sustain the family's commitment to care and strengthen the informal caregiver system (Heagarty et al., 1988). In assessing the needs of homebound elders and family members who provide the bulk of their care, it is important for health care providers, particularly home health nurses, to be aware of the dynamics of relationships between caregivers

and carereceivers (Perkins, 1987). Therefore more research in nursing needs to be conducted to shed understanding on the relationships between family caregivers and homebound elders. The problem under investigation in this study was: What is the relationship between level of burden in family caregivers and life satisfaction in homebound elders?

#### Theoretical Framework

The Roy Adaptation Model for Nursing served as the theoretical framework for the study. Roy (1980) defined adaptation as a process which involves the person's response to the environment which then specifically promotes the general goals of a person: survival, growth, reproduction, and mastery. Adaptation is achieved through autonomic processes (regulator mechanisms) and cognitive processes (cognator mechanisms) stimulated by factors in the internal and external environment. Stimuli may be focal, immediately confronting the person; contextual, mediating the response to focal stimuli; or residual, factors learned from past experience which mediate responses (Roy, 1980).

Adaptive behaviors are manifested through four subsystems, or modes, of adaptation. The body adapts to its basic biophysiological needs through the physiologic mode. The person's self-perceptions are determined by this interaction with others. As outside stimuli are perceived by the person, adaptation is achieved through the self-

concept mode. The role function mode is based on a person's performance of duties dictated by given positions within society. Finally, in relationships with others, the person adapts through the interdependence mode. Stimuli from both within and without a person cause changes in the interdependence subsystem. Roy (1980) identified interdependence as a comfortable balance in relationships established through in-depth interactions with another person. The central focus of the mode lies in the dyadic experience of interaction with a significant other which is rooted in the need for affection and nurturing, as well as the need to be nurtured (Tedrow, 1984).

Thus, the interdependence mode involves a person's ways of seeking help, attention, and affection. This mode requires the presence of a reciprocal relationship between two persons and is manifested by receptive and contributive behaviors (Roy, 1980). In his observations on interdependence, Perkins (1987) said, "Receptive behaviors include a person's ability to receive, assimilate and respond to recognition, praise and caregiving. Contributive behaviors include the person's ability to demonstrate affection, care, recognition, and praise for a significant other person in the environment" (p. 46).

Caregiving is thought to be a contributive behavior within the interdependence mode. Bunting (1989) observed that family caregivers are an extremely vulnerable group

because of their unique role. Caregivers must attempt to adapt to multiple new physical and emotional demands and often experience conflict from the pull of numerous obligations. Perkins (1987) identified that when caregivers are unable to adapt to the changes, the burden of caregiving emerges.

Tedrow (1984) purported that the impact upon the phenomenon of interdependence in the person also is influenced by advancing age and the changes in status that go with it. As the person ages, physical and emotional needs change. Adaptation to these changes and the meeting of emotional needs are accomplished through the interdependence mode (Tedrow, 1984). In his review of literature on the adaptive abilities of elders, Perkins (1987) noted that life satisfaction impacted upon adaptation in advanced age. Perkins (1987) further observed that life satisfaction often is identified synonymously with adaptation.

The compilation of the Bunting (1989), Tedrow (1984), and Perkins (1987) observations indicated the existence of a link among the contributive behaviors of caregiving, the emergence of caregiver burden, and the phenomenon of life satisfaction in elders within interdependent relationships. Roy's Adaptation Model was used to guide exploration of the dyadic interdependent relationships between burden in family caregivers and life satisfaction in homebound elders.

### Research Questions and Hypothesis

The following research questions were answered in this study:

- 1. What is the level of burden in family caregivers of homebound elders?
- 2. What is the level of life satisfaction in homebound elders living in residence with family caregivers?

One hypothesis was tested in this investigation: There is a significant inverse relationship between level of burden in family caregivers and life satisfaction in homebound elders.

#### Definition of Terms

For the purposes of this study, terms were defined as follows:

Level of burden is the extent to which caregivers perceive their emotional health, social life, and experience of stress are affected as a result of caring for the elder (Zarit et al., 1986). Operationally, level of burden is the score of family caregivers on statements on the Burden Scale (Montgomery & Borgotta, 1984).

Family caregivers are persons who consider themselves to be the primary provider of care and responsible for meeting the needs an elder cannot meet and who are considered by the elder to be the primary provider of that care (Bunting, 1989). Operationally, family caregivers are

spouses, children, or other relatives or surrogates who live in residence with a homebound elder and have assumed primary caregiving responsibilities.

Life satisfaction is the extent to which a person holds a positive self-image and regards himself as a worthwhile person no matter what his present weaknesses may be (Neugarten, 1974). Operationally, life satisfaction is the score of homebound elders on the Life Satisfaction Index-Z Scale (Wood, Wylie, & Sheafor, 1969).

Homebound elders are men and women 65 years of age and older who, due to chronic long-term illnesses, functional limitations, diminution of physical and psychological capacities and loss of a social support system, are unable to maintain residence in their homes without the assistance of others (Federal Council on Aging, 1978). Operationally, homebound elders are clients of a home health agency in rural North Alabama who meet theoretical criteria for homebound and are intellectually intact as evidenced by orientation to person, place, and time.

#### Assumptions

This study was based on the assumptions that:

1. The person is a biopsychosocial being in constant interaction with the environment (Roy, 1980).

- 2. Persons respond to the environment through physiologic, self-concept, role function, and interdependent adaptive modes (Roy, 1980).
- 3. Dyadic, reciprocal relationships of interdependence exist between family caregivers and their homebound elders.
- 4. The burden of caring is a phenomenon that can be perceived by family caregivers and can be evaluated.
- 5. The level of life satisfaction is a phenomenon that can be perceived by homebound elders and can be evaluated.

#### Summary

This chapter provided an introduction to the research problem: What is the relationship between level of burden in family caregivers and life satisfaction in homebound elders? The background of the study was described with the significance of the study to nursing science. The research questions and hypothesis were stated and the theoretical framework for the study was addressed. Principal terms were defined and the assumptions upon which the study was based were stated.

In Chapter II, current research relevant to caregiver burden and life satisfaction is reviewed and its pertinence to this study is discussed. In Chapter III, a detailed description of the design of the study is supplied, revealing how the research problem was empiricalized. In Chapter IV, the findings of the research and a summary of

outcomes of data analysis are presented. Finally, in Chapter V those findings are interpreted, and conclusions derived from the findings with implications for nursing and future research are addressed.

#### Chapter II

#### Review of Literature

The purpose of this review of literature was to determine the stance of current research relevant to caregiver burden and life satisfaction, and to identify the research perspective regarding the relationship between level of burden in family caregivers and life satisfaction in their homebound elders. In the pursuit of research indicating a link between the phenomena of interest it was discovered that the literature is replete with studies regarding family caregiver burden. For this review, attention was given only to those studies which reflect upon the reciprocal dyadic relationship between caregivers and In the 1960s and 1970s much was written carereceivers. about life satisfaction in the elderly population. Recently some rekindling of interest in life satisfaction has occurred. Only those recent studies were reviewed in the interest of this research. For this review, caregiver burden was first addressed, then life satisfaction. Finally, the limited research which was noted to draw a parallel between the phenomena was brought into focus.

#### Caregiver Burden

In 1980, a cornerstone study on caregiver burden was conducted by Zarit, Reever, and Bach-Peterson. Correlates of feelings of burden in family caregivers of 29 elders with senile dementia were explored. Most of the caregivers, interviewed in their homes, were female. The Memory and Behavior Problems Checklist was used to determine types of behaviors exhibited by the elders and the types of problems the behaviors created for the caregivers. A 29-item burden interview also was conducted, and a total burden score was calculated and analyzed. Data interpretation revealed that functional impairment and severity of behavioral problems were not associated with higher levels of burden. findings were unexpected. However, the degree of family caregiver burden was lessened with an increase in number of visits paid the dementia patient by others. These results suggested the importance of providing support to family caregivers as a critical factor in the home care of elders. It was further recommended that development of interventions to enhance the support network of the older person might prevent overwhelming burden on the family caregiver (Zarit et al., 1980).

Since that time, researchers interested in caregiver burden have sought to examine two factions of the family caregiver population: grown children and spouses.

Hawranik (1985) attempted to identify coping strategies

of middle-aged children as caregivers. In a study of 60 families, both the elder and the primary caregiver were interviewed. The Ways of Coping Checklist for the caregiver identified how individuals respond to stressful events. Social Adjustment Scale utilized for the elders measured respondents' reactions to social changes in life. Again, the majority of the caregivers were female. As with the Zarit et al. (1980) study, the variable of functional impairment in elders did not influence caregiver burden. Neither was there any significance found between coping strategies of the caregiver and the variables of health, social adjustment, and social supports for the parent. findings were assessed to be important to the gerontological nurse in that they heighten awareness to other factors which might be significantly influencing burden in middle-aged children caring for aging parents. Some of those influencing factors included being solely responsible for care of the parent and the emotional relationship between the parent and the child (Hawranik, 1985).

In a longitudinal study of 64 elderly husbands and wives, Zarit, Todd, and Zarit (1986) identified caregiver burden as a strong element in the reciprocal marital relationship after one partner becomes physically or mentally debilitated. Pruchno and Resch (1989) based an investigation on Zarit et al. (1986) and identified antecedents of burden in elderly husband and wife

caregivers. This study involved 315 persons providing home care to a spouse with Alzheimer's disease or a related Two indicators of burden (Burden 1 and Burden 2) were measured and correlated. Consistently, caregiving wives were found to be more burdened than caregiving husbands. Additionally, greater degrees of burden were assessed when there was a low degree of emotional investment in the relationship. Husband caregivers were generally more highly invested in the marital relationship than were wife The findings suggested that the demands of the caregivers. caregiver role were expressed differently by men and women. Recommendations for future research included greater attention to the relationship between caregivers and carereceivers which would lend to more complete understanding and sensitivity to the special problems of caregivers and the recipients of that care (Pruchno & Resch, 1989).

The compilation of these findings underscores the powerful role that reciprocal interpersonal relationships have in the occurrence of family member's sense of burden when caring for homebound elderly relatives. At the same time, little attention is given to the emotional responses and morale of the elders receiving that care.

#### Life Satisfaction

Miller and Russell (1980) explored elements promoting a sense of life satisfaction in nursing home residents. The

Life Satisfaction Index and an open-ended questionnaire were utilized to elicit specific elements which promoted a sense of satisfaction in 20 purposely selected elders.

Dissatisfaction was found to be influenced by the elders' being prevented from living in the manner to which they had become accustomed. The factor of close family relationships had a high correlation with life satisfaction and adaptation to nursing home placement in the elders studied. The authors' recommendations for further research included identification of elders' perceptions of the influences of environmental elements upon their satisfaction and comparisons of life satisfaction as perceived by elders and their care providers (Miller & Russell, 1980).

In a 1982 sociological study, Duff and Hong sought to identify whether quality or quantity of social interactions impacted most significantly on life satisfaction in older Americans. In the examination of 355 noninstitutionalized elders, open-ended questions were asked to determine frequency of social interactions, perceived quality of interactions with significant others, and life satisfaction. Findings suggested that it is not how often elders interact with relatives, but the perceived quality of those interactions that is important to the life satisfaction of older adults. The results of the study were consistent with earlier general findings that interpersonal relationships are of great consequence in predicting life satisfaction.

The importance of future research to consider the meaning, intimacy, and satisfaction in reciprocal social relationships with significant others was emphasized (Duff & Hong, 1982).

More recently Huss, Buckwalter, and Stolley (1988) examined 30 institutionalized elders to describe the relationship between life satisfaction and perceptions of the nurse/resident relationship. Neugarten's Life Satisfaction Index-A scale was used to measure elders' selfperceived satisfaction, independent of level of impairment. The third part of a nurse/resident relationship tool, the Trusting Relationship Area component, was adapted to evaluate residents' perceptions of nurses. Though the correlation between life satisfaction and the nurse/resident relationship was not statistically significant, higher life satisfaction scores were assessed in the presence of a confidant, even if the nurse was in the role of that confidant. Again, the phenomenon of positive interpersonal relationships was accentuated. The institution of interventions to facilitate therapeutic relationships with elders was advocated (Huss et al., 1988).

#### Caregiver Burden and Life Satisfaction

To date, only one study is known to specifically articulate an analysis of relationships between the variables of interest in this study. In a 1987 multivariate study Perkins investigated relationships among

interdependence in family caregivers, and their elders, caregiver burden, and adaptation in homebound frail elders. With the use of the Roy Adaptation Model as a foundation for the study, 72 randomly selected elder/caregiver pairs were examined. Burden in caregivers was measured through use of the Burden Scale. Adaptation in elders was gauged according to a functional assessment inventory.

Among other variables, Perkins explored two domains of burden: subjective burden, or stressful attitudes expressed about the careqiving experience; and objective burden, stressful concrete events experienced by careqivers. A statistically significant inverse relationship between subjective burden in family caregivers and self-perceived adaptation in the elders was assessed. The researcher identified that, among other factors, life satisfaction was closely associated with adaptation in elders. Subjective burden also was inversely related to mental health in the Recommendations for future research included the elders. conduction of a replication in a rural setting where community services were less readily available, and that clinical nursing research examine the effects of family care on the elderly in the home setting (Perkins, 1987).

#### Summary

In summary, a review of literature addressing research specific to caregiver burden, life satisfaction in elders, and the relationship between the phenomena was conducted.

An examination of the literature provided multiple perspectives on caregiver burden. Recent studies consistently emphasized the primacy of exploring the emotional relationship between caregivers and carereceivers (Hawranik, 1985; Pruchno & Resch, 1989; Zarit et al., 1986).

Life satisfaction in institutionalized elders has been explored more extensively than in homebound elders. Findings in the literature support that, whatever the setting, interpersonal relationships with family impact upon life satisfaction in elders (Duff & Hong, 1982; Huss et al., 1988; Miller & Russell, 1980).

While the need for examining the unique interrelationship between family caregiver's perceptions of burden and life satisfaction in homebound elders was universally found, only one study was discovered in which a correlation between the phenomena of interest was identified (Perkins, 1987). No research was found which specifically explored the relationship of burden in family caregivers and life satisfaction in elders. Therefore, building on Perkins' (1987) research in which life satisfaction was considered to be synonymous with adaptation, the relationship between level of burden in family caregivers and life satisfaction in homebound elders evolved as the focus of interest in this study.

#### Chapter III

## The Research Design

The purpose of this study was to examine the relationship between level of burden in family caregivers and life satisfaction in homebound elders. In this chapter methods used to study the variables of interest are identified. The research design, population, and sample are described, and instruments utilized for the measurement of variables are discussed. Procedures for data collection, techniques for data analysis and measures taken for the protection of human subjects are explained.

## Design of the Study

A descriptive correlational design was chosen to examine the relationship between level of burden in family caregivers and life satisfaction in homebound elders. The investigator engaged in a descriptive correlational study makes no attempt to control the independent variables. Therefore, the aim of this study was to describe the relationship between the variables rather than to infer causal relationships (Polit & Hungler, 1987).

The variables of interest in this study were level of burden in family caregivers and life satisfaction in

homebound elders. Controlled variables included the ages and mental status of the homebound elders, the geographical location in which the study took place, and the living arrangements of the caregiver/elder dyad. Intervening variables may have included the honesty of the participants and the quality of social support available to caregivers and elders.

## Research Questions and Hypothesis

The following research questions were answered in this study:

- 1. What is the level of burden in family caregivers of homebound elders?
- 2. What is the level of life satisfaction in homebound elders living in residence with family caregivers?

The research hypothesis of this study was: There is a significant relationship between level of burden in family caregivers and life satisfaction in homebound elders.

## Setting, Population, and Sample

The setting for this study was the homes of clients who received services from a private, nonprofit home health agency in Northwest Alabama. The agency has three separate branch offices which serve a two-county area. The area served by the agency is a southern rural setting where resources are limited and few formal social supports are available. While a wide margin of socioeconomic conditions

are represented within the agency's clientele, most of the elders and their families live in rustic, country homes.

Many live 20 or more miles from the nearest medical facility.

The accessible population for this study included all the clients of the agency who were over 65 years of age, and their caregivers. The specific client census varied; but for the first 11 months of 1989 it averaged 265, 250 of whom met the age criteria for this study. From that number, 112 elders met the criterion of living in residence with family caregivers. The vast majority were Caucasian, as less than 10% of the agency's population are of another ethnic background. This racial variable is typical of the general population for the catchment area.

The sample was composed of all clients and caregivers who met the criteria outlined in theoretical and operational definition of terms for this study, and who agreed to participate in the study. Such a sample of convenience was required because all eligible and willing clients had to be utilized in order to achieve a sample size adequate to support statistical analyses. The sample size was 53 caregiver/elder dyads.

#### Methods of Data Collection

Consideration of data collection methods includes attention to instrumentation and the pilot study. Specific

procedures for gathering and recording data also are addressed.

Instrumentation. The instruments utilized for measuring the variables in this study included the Burden Scale (Montgomery & Borgotta, 1985) (see Appendix A) and the Life Satisfaction Index-Z (LSI-Z) Scale (Neugarten, Havighurst, & Tobin, 1961) (see Appendix B). In addition, separate researcher-developed Participant Profiles were used to generate demographic and descriptive data for caregivers and elders (see Appendices C and D).

The Burden Scale was originally developed by Montgomery and Borgotta in 1985 at the University of Washington. scale has been revised once since that time. The Burden Scale is a 14-item, 5-point Likert scale designed for either self-administration or administration by the researcher. The scale measures two domains of caregiver burden, subjective and objective. The domains are surmised to be distinctive and may be measured independently as Pearson r correlations have indicated that the two scores measured share less than 12% of their variance. Items 1, 3, 5, 7, 9, 11, 12, and 14 specifically measured subjective burden, the degree of stress caused by specific feelings, attitudes, and emotions of family caregivers (Montgomery & Borgotta, 1985). Items 2, 4, 6, 8, 10, and 13 measured objective burden, the degree of stress caused by specific concrete events and activities in the lives of family caregivers (Montgomery &

Borgotta, 1985). By using the scale in its entirety a total burden score may be calculated.

Construct validity of the Burden Scale has been indicated on the basis of its significant correlations with other variables in studies in which it has been used. The Cronbach's alpha coefficient for the Burden Scale has shown a reliability ranging from .73 to .77 (Perkins, 1987). Because the instrument was designed for a federally funded program and is public domain, no permission for use was required.

The Burden Scale was administered using a response card given to the participants at the initiation of the questioning. Responses to statements on the instrument ranged across a 5-point continuum including the following values: (1) strongly agree, (2) agree, (3) uncertain, (4) disagree, and (5) strongly disagree. To provide for easier interpretation, items 1, 3, 5, 7, 9, 11, 12, and 14 (subjective burden items) were recoded. Recoding provided for consistency in interpretation by having a low score on any question indicate a low level of burden. Scores for subjective burden, objective burden, and total burden were calculated. The range of scores for the total level of burden on the Burden Scale is 14 (low) to 70 (high). absolute range for subjective burden is 8 to 40 (low to high) and for objective burden is 6 to 30 (low to high).

The Life Satisfaction Index-Z (LSI-Z) Scale, a modified version of the Life Satisfaction Index-A Scale, was developed by Wood, Wylie, and Sheafor in 1969. The LSI-Z Scale is a 13-item dichotomous categorical response inventory that was designed for self-administration, but may be administered by the researcher. The LSI-Z measures satisfaction with past and present life. The instrument was developed specifically for use with the aged. Wylie (1970) suggested that the LSI-Z draws out the deeper dimensions of elders' personalities by striking at social-psychological areas of human existence.

Validity has been reported at a correlation of .57
between the LSI-Z and the Life Satisfaction Ratings
Instrument. The developers reported a split-half
reliability coefficient of .79 (Wood et al., 1969).
Responses to statements on the scale were agree or disagree.
Rater judgments reveal that statements 3, 6, 10, 11, and 13
are negatively biased, and the remainder of the questions
are positively biased (Wylie, 1970). For ease of
interpretation, statements 3, 6, 10, 11, and 13 were
recoded. Each agree response then was assigned a score of
2, and each disagree response was assigned a score of 1.
Therefore, the absolute range of scores on the LSI-Z scale
was 13-26 (low to high).

Separate Participant Profiles, designed by the researcher, were used to collect demographic data about the

family caregivers and homebound elders. Information was acquired regarding age, sex, ethnic background, education, marital status, and religious affiliation of both caregivers and elders. Data regarding how the caregivers and elders were related to each other also were obtained. In addition, caregivers were asked about number of years in the current caregiving situation, previous caregiving experience, and the presence of a relief caregiver. Homebound elders were asked how many years they had been confined to home.

Pilot study. In order to test for clarity and ease of instrument administration, a pilot study with four elder/caregiver dyads was conducted by the researcher. Participants in the pilot study met all the criteria for participation in the main study. These participants' responses were included in the main study. During the pilot study, no major problems were encountered and no changes in the original plan for data collection were required. The length of time required for both interviews was found to vary but averaged the originally projected 30 minutes. The pilot study helped the researcher to improve the screening process for selecting participants, provided experience in the data collection process, and enabled the researcher to plan in detail a seminar for the other nurses who would be assisting with data collection.

Subsequently, a 75-minute seminar was conducted, with all the nurses who would be participating as research

assistants present at the meeting. The research assistants from the branch offices of the participating agency were asked to congregate at the administrative branch office, and the seminar was conducted as an in-house inservice during regular working hours.

The purpose of the seminar was to reveal the findings of the pilot study and to ensure homogeneity in methods of data collection among the 10 assistants. The research assistants were advised of the background and purpose of the study, and copies of the proposed study were made available for their perusal. Appropriate methods for obtaining informed consent were reviewed and the Participant Profiles, Burden Scale, LSI-Z scale, and open-ended questions were introduced. The nurses then practiced, in pairs, using the research instruments according to the methods outlined in The researcher observed the practice session, procedures. then reconvened the meeting, answered questions, and made the necessary clarifications. Because each nurse who would be acting as a research assistant was present at this seminar, each assistant received exactly the same information, training, and opportunity to practice prior to initiation of data collection.

<u>Procedures</u>. Protection of the rights of human subjects was regarded by first obtaining approval from the Mississippi University for Women Committee on the Use of Human Subjects in Experimentation (see Appendix E). The

purpose of the study and methods of data collection were explained to the executive director and director or nurses of the participating agency, and consent then was obtained from the executive director (see Appendix F). During the weeks of data collection, which extended from late March through late May 1990, clients of the agency and their inhome caregivers were invited to participate during routine nursing visits to the home. The researcher was identified, and the purpose of the study was explained to potential participants.

Written informed consent was obtained from the participants (see Appendix G). The research or research assistant advised the participants of the estimated length of time required to complete the interviews. The participants were assured of confidentiality, of their strictly volunteer status, and of their privilege to withdraw from the study prior to data analysis. The elders and their caregivers were informed that the services they received from the agency would in no way be affected regardless of their decision to participate in the study. Upon their agreement, participants were asked to read and sign a joint informed consent document.

Following the informed consent phase, caregivers and elders were asked to be interviewed individually.

Approximately 15 minutes were required to interview each member of the dyad.

Before interviewing the elder, the researcher or assistant ascertained mental alertness by asking the elder to identify person, place, and time. Elders who could not respond accurately were not utilized as participants in the study, and consequently neither were the caregivers of those elders.

The participant profiles containing demographic information were completed first. Response cards then were issued as points of reference for the participants as they were read statements from the scales and the interviewer documented their responses to those statements.

Participants were reminded that the issue of interest was their perceptions and that there were no correct or incorrect responses to the statements.

Upon completion of both interviews, the researcher or assistant expressed appreciation for the caregiver's and elder's participation and advised participants that a summary of findings of the study would be mailed to them upon the conclusion of the study. The researcher's card was left in the home in the event that the participants had questions or second thoughts regarding the study. A formal letter of thanks from the researcher was included when the summary of findings was mailed to the participants (see Appendix H).

## Methods of Data Analysis

Descriptive statistics were generated and examined to identify demographic characteristics of caregivers and homebound elders. Descriptive statistics included measures of central tendency and variability, and frequency distributions for the variables in the study.

Quantitative analysis was guided by the research questions and hypothesis for the study. The first research question was: What is the level of burden of family caregivers of homebound elders? This question was answered using descriptive statistics to determine total level of burden, subjective burden, and objective burden in family caregivers.

The second research question was: What is the level of life satisfaction in homebound elders living in residence with family caregivers? This question was answered using descriptive statistics relative to the level of life satisfaction in elders. Descriptive statistics of participants' responses to all items on the instruments used to measure burden and life satisfaction were generated to further clarify the answers to the research questions.

The research hypothesis for this study was: There is a significant inverse relationship between level of burden in family caregivers and life satisfaction in homebound elders. The Pearson product moment correlation statistic was calculated to identify the relationship between level of

burden in family caregivers and life satisfaction in homebound elders, as measured by the Burden Scale and the LSI-Z scale. This statistical method was chosen because the Pearson <u>r</u> is the most appropriate index when the variables being correlated have been measured on an interval scale (Polit & Hungler, 1987). The level of significance for this study was an alpha of .05.

## Summary

The research design for this study in which the relationship between level of burden in family caregivers and life satisfaction in homebound elders was explored has been described in this chapter. The setting, sample, and population for the study were defined, and the methods of data collection and analysis were related. In the subsequent chapters, the findings of the study are revealed, and the implications of those findings are discussed.

## Chapter IV

## Presentation and Analysis of Data

The purpose of this study was to examine the relationship between level of burden in family caregivers and life satisfaction in homebound elders. A descriptive correlational study was conducted among clients who received services from a private nonprofit home health agency in rural northwest Alabama. The research sample was composed of 53 caregiver-elder dyads. Data for the study were obtained through structured interviews conducted by the researcher and research assistants in the homes of the participants. Four instruments were utilized in data collection: (a) the Family Caregiver Participant Profile, (b) the Homebound Elder Participant Profile, (c) the Burden Scale (Montgomery & Borgotta, 1985), and (d) the Life Satisfaction Index Z-Scale (Wood et al., 1969).

The data collected and analyzed for this study are presented in this chapter. Characteristics of the participants are described first, followed by the outcomes of data analysis related to the research questions, outcomes of data analysis related to the research hypothesis, and additional findings.

## Characteristics of the Participants

The sample for this study was comprised of 53 pairs of homebound elders and their family caregivers. Those caregiver-elder dyads constituted the unit of analysis for this study.

Distribution of age and sex. The mean age for family caregivers was 61.3 years with a range of 22 to 82 years. For homebound elders the mean age was 80.6 years with a range of 65 to 99 years of age.

Examination of the distribution of sex of caregivers revealed that 39 (73.6%) were women and 14 (26.4%) were men. Similarly, among homebound elders 37 (69.8%) were female and 16 (30.2%) were male.

Ethnic distribution. The ethnic distribution of both caregivers and elders was ascertained. Fifty-one (96.2%) of the caregivers were Caucasian, while 49 (92.4%) of the homebound elders were Caucasian. Of the remaining participants, one caregiver was black and one was Oriental. Two black elders participated and two elders did not identify their ethnic background.

Educational background. Examination of the demographic data regarding the educational background of family caregivers and homebound elders, noted in Table 1, showed that among the family caregivers, 66% had less than a high school education. Only 13.2% had any college education.

Among the homebound elders, 78.4% had received less than a

high school education, and only 9.8% had ever attended college.

Table 1

Educational Background of Family Caregivers and Homebound

Elders

Years in School	Family Caregiver		Homebound	Elder
	<u>F</u>	*	<u> </u>	ક
Less than elementary	8	15.1	21	37.3
Less than high school	27	50.9	21	41.2
High school graduate	11	20.8	6	11.8
Some college	4	7.5	3	5.9
College graduate	2	3.8	2	3.8
Postgraduate education	1	1.9	0	0
Total	53	100.0	53	100.0

Marital status. The marital status of family caregivers was ascertained. Data analysis revealed that 36 (69.2%) of family caregivers were married at the time of the study. Seven (13.5%) of the family caregiver participants were widowed, while 8 (15.4%) were divorced. Only one (1.9%) of the family caregivers had never been married.

<u>Familial relationships</u>. In Table 2 the familial relationships between family caregivers and homebound elders

are identified. As noted earlier, 73.6% of the caregivers were female and 26.4% were male. While spouses and children represented 67.9% of family caregivers in this study, caregivers designated as "others" represented an additional 17% with small percentages distributed among various family member relationships. The others persons were either paid caregivers or friends.

Table 2
Family Caregivers' Relationship to Homebound Elders

Relationship	F	8
Spouse	17	32.1
Daughter	15	28.3
Son	4	7.5
Daughter-in-law	3	5.7
Sibling	4	7.5
Grandchild	1	1.9
Other	9	17.0
Total	53	100.0

Religious affiliation of family caregivers and homebound elders. Religious affiliations of both family caregivers and homebound elders were examined. All the homebound elders surveyed reported having some religious

affiliation, and all but one of the family caregivers were religiously affiliated.

The majority of both family caregivers (86.5%) and homebound elders (77.6%) were Protestant. The 6 (11.6%) caregivers and 9 (18.3%) elders who indicated "other" for religious affiliation specified association with the Seventh Day Adventist Church. Two (3.8%) elderly participants were Catholic.

Previous experience of caregivers. Previous experience of family caregivers in caring for elderly sick persons was reported among 30 (57.7%) of the caregiver participants.

Twenty-two (41.5%) of the caregivers denied having previous caregiving experience and one participant (1.8%) failed to answer the question.

Assistance with caregiver responsibilities. Among the family caregivers, 27 (50.9%) acknowledged that there was someone else on whom they could depend to help with their caregiver responsibilities. Twenty-five (47.2%) of family caregivers reported being solely responsible for caregiving activities and one participant (1.9%) failed to answer the question.

Length of caregiving. The length of the caregiving experience for family caregivers was ascertained. A mean of 3.7 years as family caregiver was calculated with a range of 2 months to 20 years. While 39.2% of the caregiver participants had 1 year or less experience as a family caregiver, a

total of 82.4% had been family caregivers for 5 years or less. Four caregivers (7.9%) reported having been family caregivers for the particular elders in the study for more than 10 years.

Length of homebound status. The number of years the homebound elders had spent in confinement to the home was ascertained. The mean number of years the elders had been homebound was 4.4 years with a range of 2 months to 18 years. Eight of the homebound elders could not recall their number of years of confinement. Thirteen (24.5%) had been homebound for 1 year or less. A total of 35 elders (77.8%) reported having been homebound for less than 5 years, and an additional 5 elders, for a total of 88.9% of the elders, had been homebound for less than 10 years. Four elders (7.5%) could remember having been homebound for 15 or more years.

## Analysis of Data

Two research questions were answered in this study. Descriptive statistics were generated to answer those questions.

The first research question was: What is the level of burden in family caregivers of homebound elders?

Distribution of the responses to questions on the Burden Scale are seen in Appendix I. The distribution of scores for total level of burden in family caregivers, as well as subscores on the domains of subjective and objective burden, are presented in Table 3.

Table 3

Level of Burden in Family Caregivers by Ranges and Measures

of Central Tendency

Variable	Range Low-High	Mean	Median	SD
Level of burden	15-61	39.66	40.5	9.77
Subjective burden domain <sup>b</sup>	9-37	22.32	21.5	7.13
Objective burden domain <sup>c</sup>	6-28	17.33	17.5	4.98

Note. N = 53.

<sup>a</sup>Level of Burden: Low to High (14-70). <sup>b</sup>Subjective Burden: Low to High (8-40). <sup>c</sup>Objective Burden: Low to High (6-30)

The second research question was: What is the level of life satisfaction in homebound elders living in residence with family caregivers? Distribution of the responses to questions on the Life Satisfaction Index Z Scale are presented in Appendix J.

The mean life satisfaction score was 19, with a minimum score of 14 and a maximum score of 26 (Absolute range: Low 13, High 26). The standard deviation was 2.98. The median life satisfaction score was 20, and the modal score was 19.

The research hypothesis of this study was: There is a significant inverse relationship between level of burden in family caregivers and life satisfaction in homebound elders.

The Pearson  $\underline{r}$  correlation revealed a significant inverse relationship between level of burden in family caregivers and life satisfaction in homebound elders with an alpha of .05 ( $\underline{r} = -.267$ ,  $\underline{p} = .05$ ). The research hypothesis for this study was retained.

## Additional Findings

Additional discoveries which help to clarify the characteristics of burden in family caregivers and life satisfaction in homebound elders were made during data analysis. Those findings are described in this section.

Level of burden in family caregivers. Subjective burden ( $\underline{M}$  = 22.32) was greater than objective burden ( $\underline{M}$  = 17.33). A dependent  $\underline{t}$  test showed a significant difference between mean scores on domains of subjective and objective burden [ $\underline{t}(52)$  = 5.475,  $\underline{p}$  < .001].

Levels of burden between male and female caregivers were analyzed using the ANOVA. Findings were not significant at the .05 level. Further, no significant differences were found between the levels of burden in caregivers who had previous caregiving experience and those who had no previous experience, or the levels of burden in family caregivers who had someone with whom to share caregiving responsibilities and those who did not have help.

The relationship between age of the caregiver and level of burden perceived by the caregiver were correlated using Pearson procedures. No significant relationship emerged.

Additionally, no relationship between number of years as a caregiver and level of burden was found. A nonsignificant inverse relationship was ascertained between level of burden and level of education in family caregivers.

Extrapolating high scoring responses to statements regarding the level of burden perceived by family caregivers illustrated that the presence of tension (64.2%) and the lack of time for vacations and trips (64.2%) were the greatest contributors to the experience of caregiver burden. Feelings of nervousness and depression concerning their relationship with the elderly relative (52.8%) also appreciably influenced the level of burden perceived by the majority of caregivers. Elements which contributed least to the experience of caregiver burden were feelings that the number of requests made by the relative was unreasonable (11.3%) and lack of time for the caregiver to do daily chores (11.3%).

Life satisfaction in homebound elders. The relationships between life satisfaction in homebound elders and various demographic characteristics were assessed. Life satisfaction scores between male and female elders were analyzed using the ANOVA, and no significant difference was discovered. Neither was any significance found between the number of years the elders had been homebound and scores on the Life Satisfaction Index Z Scale. Educational level and life satisfaction were evaluated using the Pearson <u>r</u>. A

significant inverse relationship between those variables was found ( $\underline{r}$  = -.284,  $\underline{p}$  = .04). Additionally, a significant positive relationship was found to exist between the age of the elder and level of life satisfaction ( $\underline{r}$  = .336,  $\underline{p}$  = .01).

When elders were specifically asked to respond to the statement, "As I look back on my life I am fairly well satisfied," 88.7% agreed. However, 82.7% of the elders did not agree that these are the best years of their lives, and 73.6% also disagreed that they were just as happy as when they were younger.

Level of burden and life satisfaction. Relationships between the separate domains of burden and the phenomenon of life satisfaction were tested using the Pearson  $\underline{r}$ . A nonsignificant inverse relationship was found between subjective burden in family caregivers and life satisfaction in homebound elders ( $\underline{r} = -.256$ ,  $\underline{p} = .06$ ). A nonsignificant inverse relationship also was ascertained between objective burden in family caregivers and life satisfaction in homebound elders ( $\underline{r} = -.157$ ,  $\underline{p} = .26$ ).

The data collected and analyzed for this study have been presented in Chapter IV. Demographic characteristics of the participants were examined. Statistical findings used to answer the research questions and test the research hypothesis were presented. Additionally, other pertinent

findings were revealed. Raw data for each variable on the research instruments may be seen in Appendices K and L.

## Chapter V

#### Outcomes of the Study

The number of homebound elders in America is growing rapidly, and the demands on family caregivers for that group also are increasing. As family members experience the burden of caring for homebound elders, stresses in the interdependent relationships between caregivers and elders may develop.

The purpose of this study was to examine the relationship between level of burden in family caregivers and life satisfaction in homebound elders. Roy's Adaptation Model was used to guide this descriptive correlational investigation.

The sample consisted of 53 family caregiver/homebound elder dyads and was drawn from among clients of a home health agency in rural northwest Alabama. Participants were interviewed in their homes during routine nursing visits. The Burden Scale was used to assess the level of burden in family caregivers living in residence with homebound elders. The Life Satisfaction Index Z Scale was used to ascertain the level of life satisfaction in homebound elders.

This chapter includes a discussion of the findings of the study. The conclusions, implications, and

recommendations which evolved from those findings also are presented.

# Summary and Discussion of Significant Findings

Demographics. The mean ages of the participants were 61.2 years for family caregivers and 80.6 years for homebound elders. Seventy-four percent of the caregivers were women. Spouses represented the largest group of family caregivers, followed, in order, by daughters, other blood relatives, then friends or paid live-in sitters. Findings regarding the age and hierarchy of family caregivers in this study are consistent with the AARP (1988) comprehensive national survey of family caregivers.

Greater than 92% of the participants in this study were Caucasian. Over 75% of both caregivers and elders were Protestant. The sample for this study was more homogeneous ethnically and religiously than those in previous similar studies (Perkins, 1987; Pruchno & Resch, 1989; Zarit et al., 1980). These ethnic and religious variables may limit the generalizability of the findings of this study to the larger population but also increase the credibility of the findings among similar ethnic and religious populations.

The levels of education for family caregivers and homebound elders were quite low. While 66% of family caregivers had less than a high school education, 79% of homebound elders never finished high school. Over 37% of

the elders never finished elementary school. Although there was no relationship between level of education in family caregivers and perceived burden, a significant inverse relationship was ascertained between level of education and life satisfaction in homebound elders. This finding may indicate that higher levels of education in elders are associated with lower levels of life satisfaction. result was consistent with that of Miller and Russell (1980), who discovered that nursing home clients with more than 12 years of education experienced greater dissatisfaction with life than those who never completed junior high school. While the inverse relationship between level of education and level of life satisfaction is incidental to this study, it is a noteworthy consideration for nurses assessing life satisfaction in elders. with higher education levels may be at greater risk for developing a decreased sense of satisfaction with life.

Research questions and hypothesis. The important role that reciprocal interpersonal relationships of family caregivers with their homebound elders plays in the occurrence of caregiver burden is well documented in the literature (Hawranik, 1985; Pruchno & Resch, 1989; Zarit et al., 1980; Zarit et al., 186). Equally well established is the impact of positive family relationships on the life satisfaction of elders (Duff & Hong, 1982; Huss et al., 1988; Miller & Russell, 1980). However, many times the

dynamics of interpersonal relationships between family caregivers and homebound elders have been overlooked by nurse researchers and nursing care providers.

The relationship between level of burden in family caregivers and life satisfaction in homebound elders was the focus of this study. A marginally significant inverse relationship between level of burden in family caregivers and life satisfaction in homebound elders emerged, thus the research hypothesis was retained. This correlation is considered weak and must be interpreted with caution but may suggest that the higher the level of burden perceived by the family caregiver, the lower the level of life satisfaction in the homebound elderly care recipient. The finding has significance since no previous studies were discovered in which these variables were empirically tested and related. Though no causation is implied, it can be surmised that nursing interventions which serve to lower the level of burden in family caregivers also may have a positive effect on the life satisfaction of elderly care recipients.

The parallels drawn from previous citations in the literature and the additional findings of this study elucidate the significance of the relationship between level of burden in family caregivers and life satisfaction in homebound elders. Perkins (1987) ascertained an inverse relationship between subjective burden in family caregivers and self-perceived adaptation in their elderly relatives.

Though no significant relationship was found between the domain of subjective burden and life satisfaction in elders in the present study, subjective burden was perceived among family caregivers as being significantly greater than objective burden. These findings lend credence to the conclusions of Zarit et al. (1980) and Hawranik (1982) that the interpersonal relationship between caregivers and elders, rather than the physical demands of caregiving tasks, affect perceived levels of burden. This presumption is further supported in this current study by the identification of the subjective factors of tension, nervousness, and depression as major elements in the experience of caregiver burden.

Lack of time to get away from the situation was a major objective factor in the experience of caregiver burden. However, no significant differences in levels of burden were ascertained between family caregivers who had someone with whom to share responsibilities and those who did not. Zarit et al. (1980) and Hawranik (1986) found that the objective tasks associated with functional impairment in elders were not associated with higher levels of caregiver burden. While providing opportunities for respite time for family caregivers continues to be an important nursing intervention, these past and present research findings imply that an intervention program which fosters the dyadic

interpersonal relationship between family caregivers and their homebound elders is even more urgently needed.

Empirical findings regarding life satisfaction in elders further demonstrates the necessity of strengthening family relationships. A positive relationship was found between advanced age and level of life satisfaction. When specifically asked to respond to the statement, "When I look back on my life I am fairly well satisfied," the vast majority of elders agreed. However, almost as many elders disagreed with the statement, "These are the best years of my life." The overwhelming consensus of responses to these statements leads to the belief that while elders were satisfied with past life, they were generally dissatisfied with present life.

In the current research literature regarding life satisfaction, the focus of attention is on the present time. However, "the dyadic interaction which occurs between caregivers and the elderly is influenced by multiple variables across a continuum of time" (Perkins, 1987, p. 23). Duff and Hong (1982), Huss et al. (1988), and Miller and Russell (1980) all suggested that life satisfaction in nonindependent elders, whether institutionalized or homebound, is contingent upon the quality of interpersonal relationships with family members. The life satisfaction findings of this study reflect the dynamics of the interpersonal relationships of elders in their present

carereceiving situation. Again, the inherent value of developing nursing interventions to facilitate positive dyadic interpersonal relationships between family caregivers and homebound elders emerges. Nurse clinicians at the primary site of home care could intervene directly by initiating counseling roles with family caregivers and homebound elders.

Before nursing interventions aimed at burden in caregivers or life satisfaction in elders can be developed and implemented, appropriate assessment of the dynamics of the caregiver/elder relationship must be accomplished. According to Roy's Adaptation Model, the interdependence mode of adaptation has as its central focus the dyadic experience of interaction with a significant other (Roy, 1980). Roy's model provided a definitive framework within which to examine the dyadic interdependent relationship between level of burden in family caregivers and life satisfaction in homebound elders in this study and could be a useful assessment tool for future research and practice with caregivers and elders.

## Conclusions

The following conclusions were derived from the findings of this study:

1. The level of subjective burden perceived by family caregivers was greater than the level of objective burden.

- 2. There was a significant inverse relationship between level of burden in family caregivers and life satisfaction in homebound elders.
- 3. There was a significant positive relationship between the age of elders and their level of life satisfaction.
- 4. There was a significant inverse relationship between level of education in elders and their level of life satisfaction.

## Limitations

The design of the study imposes certain constraints upon the generalizability of the findings. The study was conducted among families who received services from a single home health agency in a small rural area of north Alabama. The ethnic and religious characteristics of the population in that geographic location were homogenous.

The low educational level of the participants created some problems with regard to the research instruments. Some of the statements on the scales were hard for the participants to understand. The words manipulate and monotonous proved to be particularly troublesome. In the course of interpreting the statements on the research instruments, the interviewer may have inadvertently stimulated biased responses.

The study was of a sensitive nature and the research instruments introduced emotionally charged issues. The

accuracy of self-report was totally dependent on the individual participant's willingness to reveal his or her perceptions regarding the issues to the interviewer at the particular moment of the interview.

## Implications

A number of implications for nursing science were derived from this study. Implications are suggested for nursing theory, research, education, and practice.

Theory. Nursing theory is tested through research. Findings from previous studies using the Roy Adaptation Model for Nursing were validated by the findings of this research. The results of this study serve to urge the continued use of the Roy model as a conceptual framework for assessing the interdependent relationships between family caregivers and homebound elders.

Research. While the existence of caregiver burden and its indicators are fairly well documented in the research literature, the relationship of perceived burden to the well-being of elders still is poorly understood. The findings of this study suggest that more research effort is needed to gain greater insight into the needs of family caregivers and homebound elders, and into their dyadic relationships. The need to develop valid and reliable research instruments appropriate for use with low literacy populations also emerged from this study.

Education. As the demand for home care for elders continues to increase, it is essential that future nurses be prepared to respond to the needs of those elders and the family members providing care. The findings of this study demonstrate the importance of enhancing nursing curricula to include the dynamics of relationships between family caregivers and homebound elders.

Practice. In providing home care for elders, nurses must acknowledge the important role of the family caregiver. Assessment of the relationship between family caregivers and homebound elders is essential, and planning of nursing care should include family members as well as elders. While nursing interventions may necessarily be aimed at reducing the level of burden in family caregivers, the goal of intervention for the nurse in home care is enhancing the quality of life in elders. The outcome of this goal can result in supporting positive interdependent relationships between family caregivers and homebound elders.

The findings of this study contribute to existing knowledge regarding burden in family caregivers, life satisfaction in homebound elders, and the relationship between the two phenomena. The relationship and impact of burden in family caregivers and life satisfaction in homebound elders continues to be fertile ground for gerontological nursing research.

## Recommendations

Based on the findings of this study, the following recommendations are made for future research in nursing:

- 1. Replication of the study with a randomized sample.
- 2. Development of valid and reliable research instruments for use with low literacy populations.
- 3. Conduction of more research using the Roy
  Adaptation Model for Nursing as a framework for examining
  dyadic interpersonal relationships.
- 4. Conduction of research specific to the development of interventions to relieve burden in family caregivers and enhance life satisfaction in homebound elders.
- 5. Conduction of a longitudinal study to assess the development of dyadic relationships between family caregivers and elders across time.

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## APPENDIX A FAMILY CAREGIVER FEELINGS QUESTIONNAIRE

#### Family Caregiver Feelings Questionnaire

Code	#	
------	---	--

INSTRUCTIONS: Please read each statement and place a check ( ) in the box on each line which best describes <u>HOW CARING</u> FOR YOUR RELATIVE HAS AFFECTED YOUR LIFE AT THIS TIME. Select your responses from the following categories:

- (1) Strongly agree
- (2) Agree
- (3) Uncertain
- (4) Disagree
- (5) Strongly disagree

QUESTION: Since I began caring for my relative, I:

		(1)	(2)	(3)	(4)	(5)
1.	feel that I am being taken advantage of.					
2.	have time for myself.					
3.	feel stress in my relation- ship with my relative.					
4.	have personal privacy.					
5.	feel my relative attempts to manipulate me.					
6.	have time to spend in recreational activities.					
7.	feel the number of requests made by my relative is unreasonable.					
8.	have time for vacation and trips.					

- (1) (2) (3) (4) (5)

- Strongly agree Agree Uncertain Disagree Strongly disagree

		(1)	(2)	(3)	(4)	(5)
9.	have feelings of nervousness and depression concerning my relationship with my relative.					
10.	have time to do my own work and daily chores.					
11.	have feelings of tension in my life.					
12.	have feelings that the demands made by my relative are over and above what he/she needs.					
13.	have time for friends and relatives.					
14.	feel anxious about things.					

### APPENDIX B LIFE SATISFACTION INDEX-Z SCALE

#### Life Satisfaction Index-Z Scale

Here are some statements about life in general that people feel differently about. Would you listen to each statement on the list, and if you agree with it, say "AGREE." If you do not agree with a statement, say "DISAGREE."

		Agree	Disagree
1.	As I grow older, things seem better than I thought they would be.		
2.	I have gotten more of the breaks in life than most of the people I know.		
3.	This is the dreariest time of my life.		
4.	I am just as happy as when I was younger.	· 	
5.	These are the best years of my life.		
6.	Most of the things I do are boring or monotonous.		
7.	The things I do are as interesting to me as they ever were.		
8.	As I look back on my life, I am fairly well satisfied.		
9.	I have made plans for things I'll be doing a month or a year from now.		
10.	When I think back over life, I didn't get most of the important things I wanted.		

11.	Compared to other people, I get down in the dumps too often.	 
12.	I've gotten pretty much what I expected out of life.	 
13.	In spite of what people say, the lot of the average man is getting worse, not better.	 
	TOTAL SCORE	

#### APPENDIX C

FAMILY CAREGIVER: PARTICIPANT PROFILE

### Family Caregiver: Participant Profile

		Participant #
·		Disease mond cook of the following sweeting
		Please read each of the following questions
ina	IIII III C	he appropriate response as indicated.
1.	Age:	2. Sex: Male Female
	<u> </u>	
3.	Ethnic B	ackground: (Check one)
	1	. White (Caucasian)
	2	. Black
	3	. Oriental
	4	. Spanish American
	5	. Native American
	6	. White (Caucasian) . Black . Oriental . Spanish American . Native American . Other
4.		nal_Background: (Check one)
	1	. Less than elementary
	2	<ul> <li>Less than high school</li> <li>High school graduate</li> </ul>
	3	. High school graduate
	4	. Some college
	5	. College graduate
	6	<ul><li>Some college</li><li>College graduate</li><li>Postgraduate education</li></ul>
5.	Marital	Status: (Check one)
J.	Maricar i	Non married
		. Now married
		. widowed
	3	. Divorced
		. Widowed . Divorced . Separated . Never married
		. Never married
6.	How are	you related to the person for whom you are the
•		
	1	. Spouse
		. Daughter
	3	caregiver? (Check one)  Spouse  Daughter  Son  Daughter-in-law  Sibling  Grandchild
	<u> </u>	Daughter-in-law
	5	Sibling
	S	Grandchild
		Other (Specify)
		· · · · · · · · · · · · · · · · · · ·

7.	Religious Affiliation: (Check one)
	1. Protestant 2. Catholic 3. Jewish 4. Other (Specify) 5. None
8.	Have you had previous experiences (before this one) caring for elderly sick persons? (Check one) Yes No
9.	Is there anyone else on whom you can depend to help you with your caregiving responsibilities? (Check one) Yes No
LO.	How many years have you been caring for this elder? years

#### APPENDIX D

HOMEBOUND ELDER: PARTICIPANT PROFILE

### Homebound Elder: Participant Profile

		Participant #
		Please read each of the following questions appropriate response as indicated.
1.	Age:	2. Sex: Male Female
3.	Ethnic Bac 1 2 3 4 5 6.	kground: (Check one) White (Caucasian) Black Oriental Spanish American Native American Other
4.	Educations	l Background: (Check one) Less than elementary Less than high school High school graduate Some college College graduate Postgraduate education
5.	How long h	ave you been confined to your home? rs
6.	most of the	u related to the person who cares for you e time? Spouse My daughter My son My daughter-in-law Sibling My grandchild Other (Specify)
7.	Religious /	Affiliation: (Check one) Protestant Catholic Jewish Other (Specify) None

# APPENDIX E APPROVAL OF COMMITTEE ON USE OF HUMAN SUBJECTS IN EXPERIMENTATION



Vice Fresident for Academic Attairs P.O. Box W-1603 (601) 329-7142

Harch 21, 1990

Hs. Lorraine G. Hamm Division of Nursing Campus

bear Hs. Hamm:

The Committee on Use of Duman Subjects in Experimentation has recommended approval of your proposal "Relationship Between Subjective Burden in Family Caregivers and Life Satisfaction in Homebound Elders." I am happy to approve their recommendation.

Sincerely,

Dorothy Burleslaw

Dorothy Burdeshaw Interim Vice President for Academic Affairs

DB:Wr

ce: Hrs. Hary Pat Curtis

# APPENDIX F MEMORANDUM OF AGREEMENT CONCERNING RESEARCH STUDY

### Memorandum of Agreement Concerning Research Study

T.	it	le	of	St	udv	
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Relationship of Family Caregiver Subjective Burden and Life Satisfaction in Homebound Elders

Name of Agency:

Southern Rural Health Care Consortium

Study discussed with and explained to:

Margaret Scott, Executive Director

Carol Sumerel, RN, Director of Nurses

The nature and purpose of this study have been defined. I understand that all information will be kept confidential and that this institution may withdraw at any time during data collection.

SOUTHERN RURAL HEALTH CARE CONSORTIUM
Executive Director
Researcher

### APPENDIX G INTRODUCTORY LETTER AND INFORMED CONSENT

### Introductory Letter and Informed Consent

I am a registered nurse and graduate Mississippi University for Women. I needs of elderly people and the famithem. This information will help hobetter understanding of the needs of caregivers. The study has been apprand the Executive Director of Southe Consortium.	am doing a study on the ly members who care for me health nurses gain a the homebound and their oved by the University
I would like your permission for you extra questions during a regular visweeks. Talking with the patient and a total time of about 30 minutes.	it within the next few
I need to be very sure that I have y your answers to the questions in my all the information you share will be dential and will be used only for the No names will be used, and the information as a group. Your decision to be in voluntary and will in no way affect from Southern Rural Care Consortium. The study at any time before all the and analyzed (data analysis). If you findings will be sent to you upon continuations.	study. Be assured that e kept strictly confi- e purposes of the study. mation will be reported the study is completely the care you receive You may withdraw from information is combined u wish, a summary of the
If you would like more information being study, please feel free to contact Thank you very much for being willing request.	t me at (205) 356-9301.
Sincerely,	
Lorraine G. Hamm, RN, BSN	
I have read the above letter. I und the study and the conditions of my b	
Signature of Caregiver	Date
Signature of Client	Date

# APPENDIX H SUMMARY OF FINDINGS AND LETTER OF THANKS TO PARTICIPANTS

### Summary of Findings and Letter of Thanks to Participants

Dear	:	:

Thank you for your recent participation in my study for graduate school at the Mississippi University for Women. The study has now been completed. You will find a summary of the results of the study enclosed. A more complete listing of the results are available upon your request. Again, your participation and cooperation are very much appreciated.

Sincerely,

Lorraine G. Hamm, RN

#### Summary of Study Results

- . The average age of family caregivers was 61 years.
- . The average age of homebound elders was 81 years.
- . The majority of family caregivers were female (73.6%) and were married (69.2%).
- . Spouses were most often the caregiver (32%), then daughters (28%).
- . The average number of years spent as a caregiver was 3.7 years.
- . The average number of years the older people had been homebound was 4.4 years.
- . The level of stressful feelings experienced by most family caregivers was moderate.
- . Most of the homebound older people were fairly well satisfied with life.
- . As the level of stressful feelings in family caregivers increased, the level of life satisfaction in older people decreased.

## APPENDIX I RESPONSES TO STATEMENTS REGARDING LEVEL OF BURDEN IN FAMILY CAREGIVERS

Responses to Statements Regarding Level of Burden in Family Caregivers

	Responses					
Statement	Agree		Uncertain		Disagree	
	<u>F</u>	8	<u>F</u>	8	<u>F</u>	ક
Feel that I am being taken advantage of	15	28.8	4	7.5	34	64.1
Have time for myself	27	50.9	6	11.3	20	37.7
Feel stress in my relationship with my relative	21	39.6	3	7.5	29	54.7
Have personal privacy	28	52.8	6	15.1	19	35.8
Feel my relative attempts to manipulate me	13	24.5	4	13.2	36	67.9
Have time to spend in recreational activities	19	35.8	8	7.5	26	49.1
Feel the number of requests made by my relative is unreasonable	6	11.3	7	5.7	40	75.4
Have time for vacation and trips	15	28.2	4	7.5	34	64.2
Have feelings of nervousness and depression concerning my relationship with my relative	28	52.8	3	5.7	22	41.5
Have time to do my own work and daily chores	38	71.7	6	11.3	9	17.0
Have feelings of tension in my life	34	64.2	4	7.5	15	28.3
Have feelings that the demands made by my relative are over and above what he/she needs	11	20.8	2	3.8	40	75.4
Have time for friends and relatives	36	67.9	6	11.3	11	20.8
Feel anxious about things	22	41.5	3	5.7	18	34.0

# APPENDIX J RESPONSES TO STATEMENTS REGARDING LIFE SATISFACTION IN HOMEBOUND ELDERS

Responses to Statements Regarding Life Satisfaction in Homebound Elders

		Responses			
	Agree		Disagree		
Statement	<u>F</u>	8	<u>F</u>	8	
As I grow older, things seem better than I thought they would be.	27	44.1	26	50.9	
I have gotten more of the breaks in life than most of the people I know.	36	67.9	17	32.1	
This is the dreariest time of my life.	24	45.3	29	54.7	
I am just as happy as when I was younger.	14	26.4	39	73.6	
These are the best years of my life.	9	17.3	44	82.7	
Most of the things I do are boring or monotonous.	25	47.2	28	52.8	
The things I do are as interesting to me as they ever were.	23	43.4	30	56.6	
As I look back on life, I am fairly well satisfied.	47	88.7	6	11.3	
I have made plans for things I'll be doing a month or a year from now.	15	28.3	38	71.7	
When I think back over life, I didn't get most of the important things I wanted.	26	49.1	27	50.9	
Compared to other people, I get down in the dumps too often.	26	66.0	18	34.0	
I've gotten pretty much what I expected out of life.	35	66.0	18	34.0	
In spite of what people say, the lot of the average man is getting worse, not better.	14	26.4	39	73.6	

# APPENDIX K RAW DATA FOR INDIVIDUAL STATEMENTS ON THE BURDEN SCALE

Raw Data for Individual Statements on the Burden Scale

Statement No.	<u>M</u>	SD
A1	3.491	1.171
A2	2.868	1.256
А3	3.245	1.329
A4	2.811	1.272
<b>A</b> 5	3.509	1.353
<b>A</b> 6	3.189	1.257
A7	3.830	1.051
A8	3.642	1.371
A9	2.830	1.464
A10	2.358	1.058
A11	2.453	1.202
A12	3.717	1.150
A13	2.472	.953
A14	2.604	1.246

## APPENDIX L RAW DATA FOR INDIVIDUAL STATEMENTS ON THE LIFE SATISFACTION INDEX-Z SCALE

Raw Data for Individual Statements on the
Life Satisfaction Index-X Scale

Statement No.	<u>M</u>	<u>SD</u>
<b>B</b> 1	1.509	.505
B2	1.679	.471
В3	1.453	.503
B4	1.264	.445
В5	1.170	.379
В6	1.472	.504
В7	1.434	.500
В8	1.887	.320
В9	1.283	.455
B10	1.491	.505
B11	1.491	.505
B12	1.660	.478
В13	1.264	.445