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THE PERCEPTION OF FAMILY SUPPORT RELATED TO POSITIVE
AND NEGATIVE BELIEFS ABOUT CAREGIVING AMONG A
GROUP OF DAUGHTERS CARING FOR ELDERLY MOTHERS

presented by

Carol Ann Wank

has been accepted towards fulfillment
of the requirements for

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Barbara Given
Major professor

Date____________________

THE PERCEPTION OF FAMILY SUPPORT RELATED TO POSITIVE AND NEGATIVE BELIEFS ABOUT CAREGIVING AMONG A GROUP OF DAUGHTERS CARING FOR ELDERLY MOTHERS

By

Carol Ann Wank

A THESIS

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ABSTRACT

THE PERCEPTION OF FAMILY SUPPORT RELATED TO POSITIVE AND NEGATIVE BELIEFS ABOUT CAREGIVING AMONG A GROUP OF DAUGHTERS CARING FOR ELDERLY MOTHERS

By

Carol Ann Wank

This project is a descriptive correlational study of one hundred twenty daughters caring for elderly mothers post hospitalization. Subjects were recruited from twenty seven hospitals and visiting nurse associations as part of a larger study conducted at Michigan State University. The goal of this project was to examine the effects of perceived family support on positive and negative beliefs about caregiving. The project utilizes secondary analysis of data. Quantitative data analysis was used to look for correlations among the dependent variables of positive and negative beliefs about caregiving and the independent variable family support. Demographic data was used for descriptive purposes to describe the sample. It was hypothesized that family support will be positively associated with positive beliefs about caregiving and family support will be negatively associated with negative beliefs about caregiving. Correlations between the study variables in this study were not significant. Family support was perceived to be low by caregivers. Positive beliefs were more strongly expressed than negative beliefs.

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INTRODUCTION

Caregiving has been the focus of a significant portion of the gerontological research in the past years. It is a well published fact that the population is aging. According to the American Association of Retired People (1994), in 1993 there were 32.8 million individuals over the age of sixty five with 19.5 million who were women. Currently depending on the source, only about five to six percent live in institutions and the remainder are living in the community either independently or receiving assistance from family members or other sources. Brody (1985) has described parent care as a normative family process, however it is not a developmental stage that fits neatly into the life cycle. Parent care occurs at different times for different individuals and may present different challenges for the individual involved.

Family members, specifically daughters, provide a significant amount of care to the elderly. Women have historically been the caregivers of society and caring has been a practice associated almost exclusively with women. Gilligan (1982) has done extensive research on the differences between women and men with regard to relationships. Women are socialized differently from birth with more of an emphasis on the "relationship" aspects of life whereas men are more conscious of the rules and issues of right and wrong. Women seem to be nurtured as caregivers and this societal emphasis makes it difficult to give up the caregiving role. Gender differences with the caregiving experience are documented in the literature with women reporting a more stressful experience than men (Horowitz, 1985; Strawbridge & Wallhagen, 1991). Because of the socialization by society, mothers and daughters share a special relationship and have been singled out for study by numerous authors. The mother-daughter relationship is described by Barnett, Kibria, Baruch, and Pleck (1991) as "...the longest lasting relationship they are ever likely to have" (p. 29).

While an abundance of literature has been written on the primary caregiver experience, less has addressed the influence of family support on the caregiver. Several studies have supported the concept that perceived satisfaction with social support lessens the psychological distress of caregiving (Ballie, Norbeck, & Barnes, 1988; George & Gwyther, 1986). These studies considered the effects of all social support and did not specifically study the effects of family support. Social support in these studies included both formal such as community services as well as informal such as friends. Identifying and isolating specific sources of support may be useful in planning interventions useful in adapting to the caregiver role.

Limited research is available on the roles of sibling interaction and perceived support in the caregiving role. Brody Hoffman, Kleban, and Schoonover (1989), studied perceptions of caregiving among a group of daughters and

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local siblings. This study reported, "Caregivers prominent in the uplifts factor had a strong sense of receiving help from their families and siblings, tended to have more local siblings and tended not to experience an overall sense of strain from hassles" (Brody et al., 1989, p. 536).

Limited research is available on the roles of sibling interaction and perceived support in the caregiving role. Brody, Hoffman, Kleban, and Schoonover (1989), studied perceptions of caregiving among a group of daughters and local siblings. This study reported, "Caregivers prominent in the uplifts factor had a strong sense of receiving help from their families and siblings, tended to have more local siblings and tended not to experience an overall sense of strain from hassles" (Brody et al., 1989, p. 536). Uplift factors included such things as moral support, someone to talk to, approval, dependability and understanding from siblings.

Negative and positive beliefs about caregiving have been identified in the literature. Negative beliefs have been identified as caregiver burden, caregiver stress, and caregiver strain. These beliefs include items such as inconvenience, confinement, family adjustment, competing demands on time, feelings of being overwhelmed, physical strain, and financial strain (Bunting, 1989; Lawton, Kleban, Moss, Rovine, & Glicksman, 1989; Schoonover, Brody, Hoffman, Kleban, 1988; Zarit, Reever, & Bach-Peterson, 1980). Positive beliefs have been identified as gratifications of caregiving such as experiencing moments of warmth, comfort and pleasure, feeling appreciated, feeling closer to care recipient, affection, and enjoyment of the relationship (Lawton et al., 1989; Walker, Shin, & Bird, 1990; Walker, Shin, Bird, & Jones, 1990; Wood, 1990).

Purpose of the Study

The purpose of the study was to explore and describe the relationship of family support to positive and negative beliefs about caregiving among a group of new caregiving daughters providing care to their aging mothers post hospitalization.

The rationale for the development of this study was to increase awareness of the influence of perceived family support on positive and negative beliefs about caregiving among a group of adult daughter caregivers. The results of this study will provide information to health care professionals that may improve communication and educational counseling to adult daughters regarding family support in care for the elderly. The study will be important in primary care to assist daughters providing care to elderly mothers to develop strategies that promote successful transition to the caregiving role. The study was designed to study the perceptions of family support by the adult daughter caregiver.

This study is based on a secondary analysis of data from the family care study by Joanne Pohl (1992) that focused on the mother-daughter relationship and the adult daughter's commitment to the caregiving role. The Pohl (1992) sample is a sub-sample of a larger study entitled, "Caregiver Responses to Managing Elderly Patients at Home" conducted at Michigan State University and funded by the National Institute on Aging (R01 AG0658406, Given, 1988) that examined caregiver responses to managing elderly patients at home. The focus of this study will be on the positive and negative beliefs about caregiving identified in the Pohl (1992) study and will investigate the relationship between perceived family support and positive and negative beliefs about caregiving.

Statement of Purpose

The purpose of this study was to examine the question: **Among a group of caregiving daughters providing care to elderly mothers, is there a relationship between the perception of family support for the caregiving role and positive and negative beliefs about caregiving?**

CONCEPTUAL FRAMEWORK

Introduction

The conceptual framework for this study is presented in this chapter. The purpose of the conceptual framework is to provide a systematic structure for describing the concepts under investigation. In the conceptual framework an integration of the Roy Adaptation Model (1992) and the concepts of positive beliefs about caregiving, negative beliefs about caregiving and family support will be discussed.

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The chapter is divided into three main sections. First, the conceptual definitions of positive beliefs about caregiving, negative beliefs about caregiving, and family support are presented. Second, an overview of the Roy Adaptation Model (1991) is described. Third, a discussion and model of the relationship between the variables and Roy Adaptation Model (1991) will be provided.

Positive Beliefs About Caregiving

Positive beliefs about caregiving have not been frequently cited in the literature. In a study about perceptions of relationship change and caregiver satisfaction Walker, Shin, and Bird (1990) describe gratifications of caregiving as experiencing moments of warmth, comfort and pleasure as well as enjoying being with and feeling appreciated by the care receiver.

Lawton, Kleban, Moss, Rovine, and Glicksman (1989) also describe positive aspects of caregiving such as raising caregiver self-esteem and feeling closer to care recipient. Wood (1991) described a positive aspect of caregiving as caregivers receiving a sense of fulfillment in knowing that they were putting forth their best effort in assisting their loved one. Walker, Pratt, Shin and Jones (1990) cite affection, closeness, and enjoyment of the relationship as strong motivators of intergenerational contact and aid.

Archbold, Stewart, Greenlick, and Harvath (1990) refer to mutuality as a positive aspect of caregiving. Mutuality refers to the ability to find gratification and meaning in

the caregiving situation as well as the ability to perceive the care receiver as reciprocating by virtue of their existence.

For the purposes of this study, positive beliefs about caregiving describe positive feelings about the caregiving situation including feelings of enjoyment, satisfaction, mutuality, and willingness to care for mother.

Negative Beliefs About Caregiving

There has been an abundance of literature which documents the negative aspects of caregiving. Negative aspects of caregiving have been referred to as caregiver burden, caregiver stress, caregiver distress, or caregiver demands. Lawton et al. (1989) describe caregiving distress as poor health, isolation, end-of-one's rope feeling, loss of control, fatigue, depression and feeling trapped. Caregiver distress may also consist of infringement of the life style because of the demands of care, negative family relations, lack of privacy, restriction on visiting and preemption of space. In a study of geographically distant children, Schoonover, Brody, Hoffman, and Kleban (1988) describe negative feeling of caregiving as feeling helpless, drained, or overwhelmed, and having difficulty in setting priorities associated with the mother's need for help.

Robinson (1983) described negative beliefs (stressors) as inconvenience, confinement, family adjustments, changes in personal plans, competing demands on time, emotional adjustment, upsetting behavior, the parent seeming to be a

different person, work adjustments, feeling of being completely overwhelmed, sleep disturbance, physical strain, and financial strain. Zarit, Reever, and Bach-Peterson (1980) described the negative impact on caregiving as the caregiver's lack of time for oneself, the excessive dependency of the patient on the caregiver, and the caregiver's fear of further deterioration in the patient's behavior.

Bunting (1989) describes the negative consequences of caregiving for the caregivers themselves as including the emotional stresses of coming to terms with the changing role and capability of the older person; the restrictions on time and freedom; the economic burdens, including the loss of curtailment of employment; and the detrimental effects of the caregiver's marital, family, and social relationships.

For the purposes of this study, negative beliefs about caregiving describe negative responses to the caregiving situation such as feelings of discouragement, entrapment, and resentment in caring for the aging mother.

Family Social Support

Family social support is a difficult concept to define. Roy (1991) defines social support as "Support systems are persons, groups, or animals that contribute to meeting a person's interdependence needs. Support systems provide the same function of giving and receiving love, respect and value" (p. 388).

Kane (1988) follows the systems theory and defines family social support as "an ongoing pattern of social relationships between the family and its social environment that reflects interdependence" (p. 20). Kane makes three assumptions regarding social support which are as follows: 1) the family is a system; 2) social support is a social process; and 3) social support is positive and helpful. Kane does acknowledge that social support may at times be negative, but this is considered to be an additional stressor.

Kane describes three factors that are present of social support is occurring; reciprocity, advice/feedback, and emotional involvement. Reciprocity refers to the fact that an individual is involved in a network of mutual obligation. According to Kane (1988), "Reciprocity is demonstrated by behaviors in which an individual shares resources with others and is able to ask for and receive help from others" (p. 22). Advice/feedback are also factors in social support. According to Kane (1988), "the family is in the process of sharing perceptions of itself with others and likewise or receiving evaluations from others as to how the family is perceived" (p. 22). Emotional involvement is the third interactional component and according to Kane (1988), connotes "the positive emotional bonds between the family and others such as love, caring, warmth, and compassion" (p.22).

Russell and Cutrona (1984) developed a model for social support based on the Weiss (1974) model. The following six items are provisions of social relationships as described by Weiss: 1) Attachment: Provided by relationships where the person receives a sense of safety and security; 2) Social Integration: Provided by a network of relationships where individuals share interests and concerns; 3) Reassurance of Worth: Provided by relationships where the person's skills and abilities are acknowledged; 4) Reliable Alliance: Provided by relationships where the person can count on assistance under any circumstances; 5) Guidance: Provided by relationships with trustworthy and authoritative others who can provide advice; and 6) Opportunity for Nurturance: Provided by relationships where the person feels responsible for the well-being of another (Russell & Cutrona, 1984, p. 12).

There are similarities in the description of social support that have been provided. Interactional processes are difficult to measure. For the purposes of this paper, family support will describe the caregivers perceptions of the family's willingness to help, spend time with mother, offer emotional support to the caregiver, and work with the caregiver as needed.

Conceptual Framework

The Roy Adaptation Model will be used as the conceptual framework for this study. Roy (1991) described the individual as an adaptive being comprised of four distinct

modes. The modes are as follows: a) the physiologic mode which is associated with the way a physical being reacts to stimuli from the environment; b) the self concept mode which focuses on the psychological and spiritual aspect of the person; c) the roles mode which focuses on the roles an individual plays in society; and d) the interdependence mode which focuses on the relationships the individual is involved in.

Roy (1991) describes the environment as including the conditions, circumstances, and influences that surround and affect the development and behavior of the person. Roy uses the term stimulus to describe this behavior. The Roy model addresses three distinct types of stimuli. Focal stimuli can be described as "the internal or external stimulus most immediately confronting the person" (p. 7). Contextual stimuli are "all other stimuli present in the situation that contribute to the effects of the focal stimuli" (p. 9). Contextual stimuli are all the environmental factors that are present to the person from within or without but are not the center of the person's attention and/or energy. Residual stimuli are "environmental factors within or without the person whose effects in the situation are unclear" (p. 9).

Adaptive behavior reflects a positive response to internal and external environmental change while ineffective behavior reflects a negative response. These responses act as feedback or further input to the system allowing the

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individual to decide whether to increase or decrease efforts to cope.

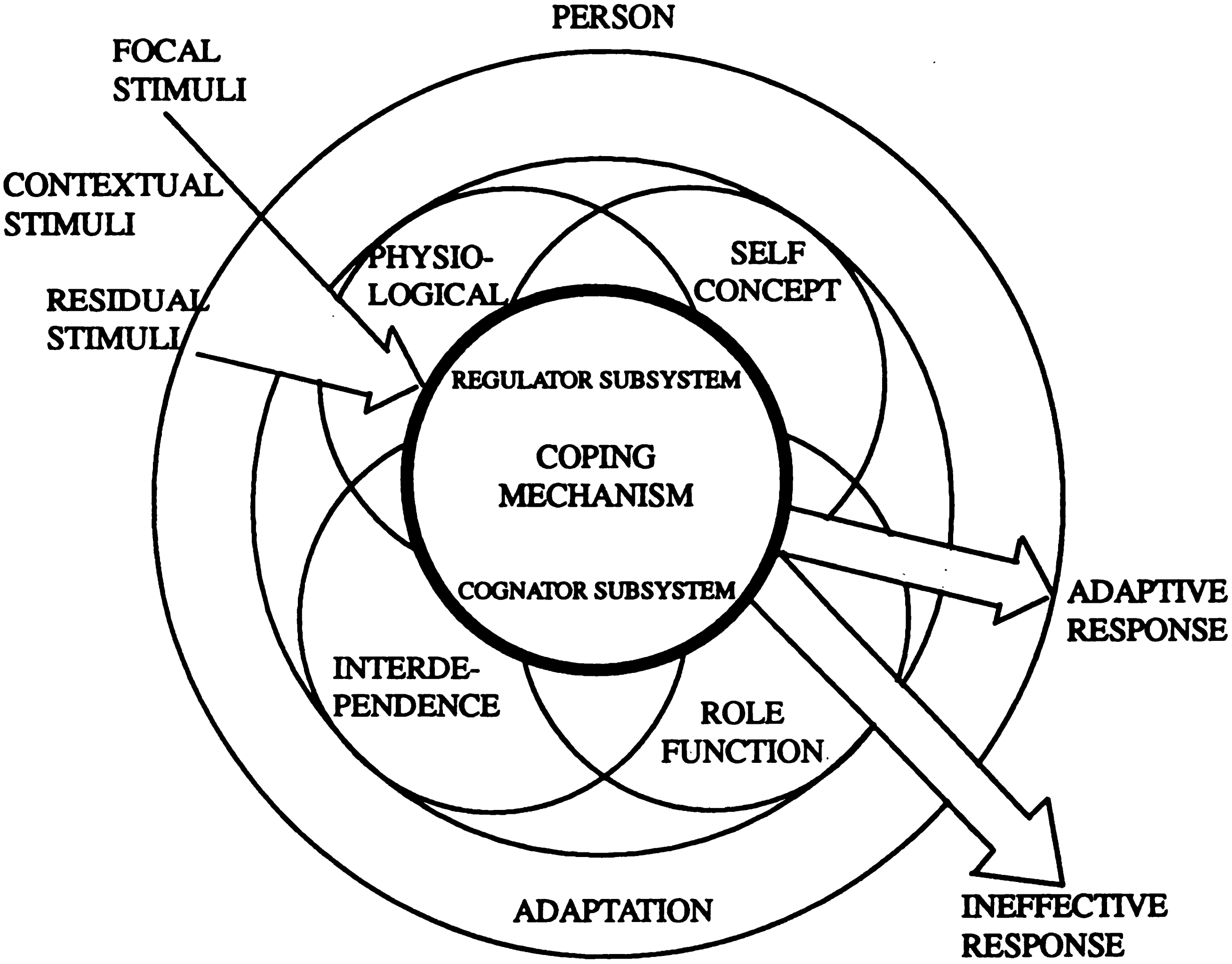
Coping mechanisms are defined as innate or acquired ways of responding to the changing environment. Roy further divides the innate and acquired coping mechanisms into two major subsystems termed as the regulator and cognator subsystems. The regulator subsystem responds automatically through neural, chemical and endocrine coping processes. The second major coping process, the cognator subsystem, responds through cognitive-emotive channels such as perceptual/information processing, learning, judgment, and emotion (p. 14).

Roy describes the goal of nursing as the promotion of adaptation in each of the four modes thereby contributing to the person's health, quality of life, and dying with dignity (p. 20).

See Figure 1 for the Roy Model of the person. Stimuli (focal, contextual, and residual) affect the person represented by the four modes. The person's coping mechanisms respond to the stimuli and produce a response which is either adaptive or ineffective and acts as feedback to the system for further evaluation and response.

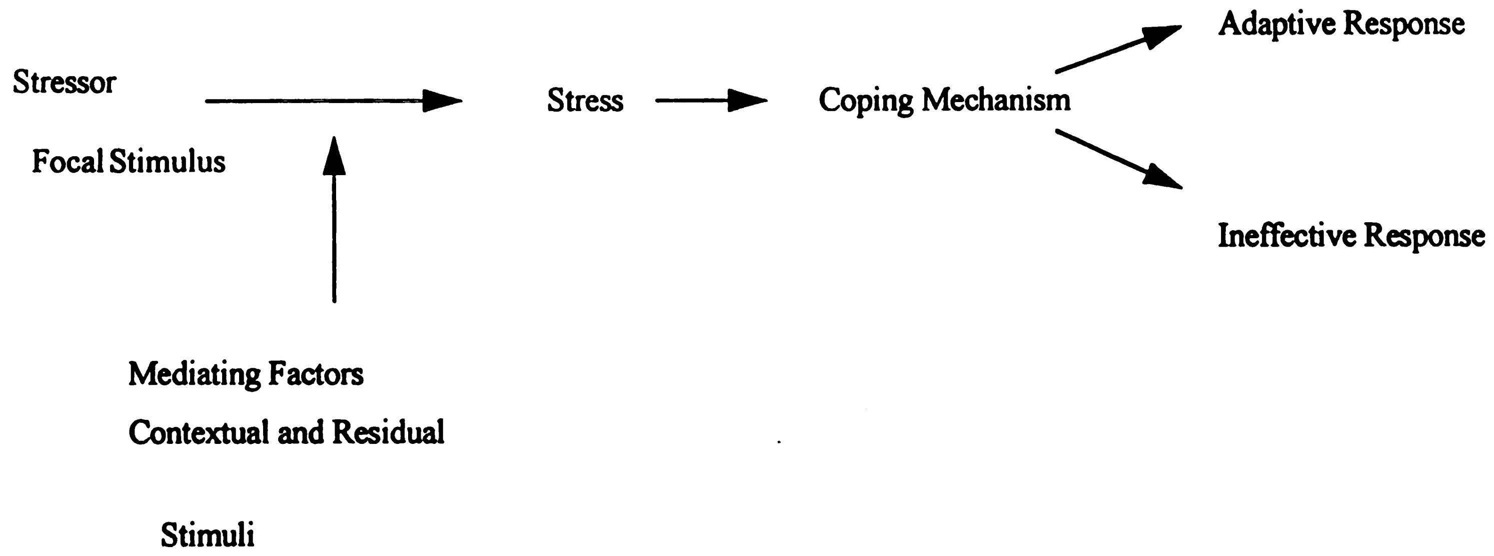
The model proposed for this study is based on the stress adaptation process described by Roy. See Figure 2 for the adaptation of the Roy Stress Model used in this study. The Roy Adaptation model assumes a holistic approach to the person and his/her relationship to stress. Stress is

Figure 1. The Person as an Adaptive System



Adapted from Roy, C. and Andrews, H. (1991).

Figure 2. Adaptation of the Stress Adaptation Process



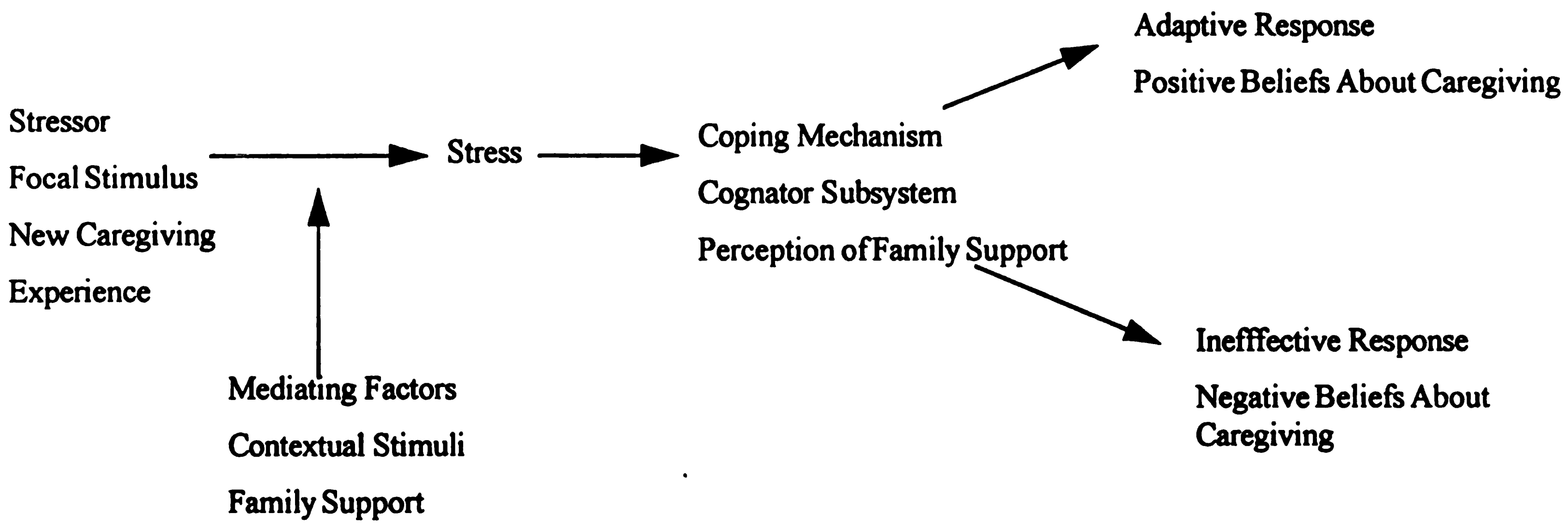
Based on Roy Model of Stress Adaptation in Roy, C. and McLeod, D. (1981)

viewed as a general term given to the transaction between the environmental demands for adaptation and the individual's response. All the components of the stress adaptation process are dynamic processes continually changing over time.

According to Roy (1991), stress is two dimensional in the process of adaptation. On the input side of the stress interaction, stressors are focal stimuli, mediated by the contextual or residual factors, and determine the individuals adaptation level. Cognitive appraisal is central in determining which stimuli constitute stress for each individual. Stress interaction, involves activation of coping mechanisms which produce adaptive or ineffective behaviors.

See Figure 3 for the model proposed for this study. The main stimuli in this model or the focal stimuli is represented by the mother daughter new caregiving situation itself. In this model, the "new caregiving experience" will be assumed to be a stressor. Caregiving has been documented in the literature to be a stressful event. In this model family support is a mediating factor which affects the caregiving situation. Family support is considered to be a contextual stimuli. As previously discussed, family support is considered to be generally positive but may have a negative or additional stressful additive if negative interactions are present. In the model, stress is a result of the mother-daughter caregiving experience and family

Figure 3. The Stress Adaptation Process as Related to Caregiving and Family Support



Adapted from Roy Model of Stress Adaptation in Roy, C., and Andrews, H. (1991).

support is considered the mediating factor which may increase or decrease the stress. Coping mechanisms considered in the model are a result of the cognator subsystem specifically the perception of family support. The adaptive response in this model is represented by the positive beliefs about caregiving while the ineffective response represents the negative beliefs about caregiving. Analysis for this project will focus on the concepts of perceived family support and negative and positive beliefs about caregiving.

REVIEW OF THE LITERATURE

Introduction

In this chapter a review of the literature relevant to mother-daughter caregiving, positive beliefs about caregiving, negative beliefs about caregiving and family support including emotional support is presented. The review includes a discussion of the research methodologies, statistical findings, and the strengths and limitations of the studies.

Daughter-Mother Caregiving

Walker and Pratt (1991) studied mother-daughter aid patters to determine if aid given by daughters to mothers can be viewed as part of a continuum of aid rather than as a dramatic shift in the intergenerational relationship. The sample of daughters (n=182) consisted of a control group (n=43) who had self sufficient elderly mothers who were able to meet daily needs of their own and a comparison group

(n=139) who were considered to be primary caregivers to their mothers. To be considered for the caregiving group, mothers were dependent on daughters for at least one of the following forms of assistance: laundry, transportation, meal preparation, housekeeping, personal care or financial aid.

Data was gathered through a face-to-face structured interview in the home for which each daughter received twenty dollars. In addition, appointments were made for nine telephone interviews over the next two months to obtain additional task and activity reports. The instrument used for the study was an adaptation of an instrument designed for a previous study developed to measure the division of household labor in marriage. Eight categories of instrumental assistance were measured as well as three categories of psychological aid. Reliabilities were reported for each category.

The groups of daughters were compared with t-tests. In all but two of the instrumental aid categories, outdoor tasks and financial aid, caregiver daughters reported greater frequencies of instrumental aid than did control daughters. According to Walker and Pratt (1991), "Clearly demonstrated, however, is that both control and caregiving daughters gave significant amounts of aid to their mothers in every category of aid assessed." (p. 8). Analysis of psychological aid, revealed no differences between groups in the average number of leisure activities over the eleven day report. Caregiving daughters did report a greater frequency

of psychological support and contact with their mothers than did the control daughters. Again Pratt and Walker (1991) report that both groups gave significant amounts of psychological aid to mothers in all three categories. Walker and Pratt concluded that caregiving seems to be a continuum as well as an extension of earlier intergenerational assistance.

Strengths of the study included the comparison group in an attempt to understand the relationship of intergenerational aid and caring. Limitations of the study include the cross-sectional design which does not allow conclusions to be drawn about transition from intergenerational assistance to caregiving. Non random sampling does not allow for generationalizations to the general population.

Horowitz (1985) presented a study of one-hundred thirty one children identified as the primary caregiver relative to an older parent and examined how sons differentially perform and experience the caregiving role as compared to daughters. Questions considered in this study include the following: 1) Having taken on the primary caregiving role, do sons and daughters differ in the type and extent of assistance provided? 2) Do they differ in their respective perceptions of the social and emotional consequence of caregiving?

The subjects were recruited from four community based agencies in New York City which included a daycare center, a homemaker agency, a local chore program, and a visiting nurse service. Programs were chosen to provide access to older people exhibiting a range of service needs and service utilization. Selection process for participation included a random sample from all four agencies with the older adult being contacted to supply the name of a primary caregiver and give permission to contact the caregiver. The next step involved contacting the relative who consented to participate which resulted in a usable sample (n=203) of which 65 percent were adult children, 76 percent who were daughters and 24 percent who were sons.

Data were collected via an in depth, structured interview with the caregiving relative that lasted approximately two hours. The major dependent variables in the study were caregiving involvement and caregiving consequences.

Caregiving involvement was defined as the objective level of time and task commitment and operationalized by a twelve item scale. Scale items included the frequency of face to face and telephone encounters and the extent of help given in each of the following: transportation, household help, shopping, meal preparation, personal care, health care, financial management, emotional support, and financial assistance. Internal consistency showed Alpha Coefficient= 0.82.

Caregiving consequences refer to the relatives' perception of how caregiving has affected their social, emotional and familial lives. Twenty nine items were included in the measure. The alpha co-efficient was .88 for the scale.

In terms of caregiving involvement, "with the exception of health care, daughters were significantly more likely to help their parents with all services calling for "hands on" assistance such as transportation, household chores, meal preparation, and personal care" (Horowitz, 1985 p. 614). Scores on the caregiver involvement scales indicated sons spent considerable less time in care of elderly parent than did daughters. When sons did take on the role of primary caregiver, they tended to have limited time and task commitment then did daughters.

In terms of caregiving consequences sons tended to be less negatively affected than daughters in the following areas: 1) less likely to believe they had to give up anything (32% sons, 60% daughters); 2) believe they neglected family responsibilities (9% sons, 31% daughters); 3) time for leisure negatively affected (22% sons, 56% daughters); 4) emotional state had changed for the worse (31% sons, 59% daughters); 5) plans for the future had been negatively affected (16% sons, 43% daughters). Horowitz reported the experience of caregiving for an older parent remained one of considerably greater strain for an adult daughter than for an adult son.

Strengths of the project included the attempt to obtain a random sample. Instruments used for the study were reliable. A limitation of the study was that the population

was identified by participation in a service organization which is not true of many caregiving situations and limits generalization to the general population.

The Pohl (1992) study on which this study is based was a quantitative/qualitative study that looked at the stability of the mother-daughter relationship during the transition to caregiving. The specific aim of the study was to examine longitudinally the relationship between mother-daughter attachment, mother-daughter conflict, mother's level of disability and an adult daughters commitment to caregiving measured at two points of time. The sample consisted of ninety eight caregiving daughters. Measurement tools used in the study included: 1) Thompson and Walker's Attachment Scale (1984) which was a nine item scale used to measure mother-daughter attachment (alpha=0.85); and 2) Boyd (1987) Conflict Scale which was an eight item scale used to measure conflict (alpha=0.84). (Additional Scales will be described in positive and negative beliefs sections respectively.)

The Pohl (1992) study was a longitudinal study which took measurements within the first three months of caregiving and then again three months later. Data were obtained by phone interview and follow up questionnaires.

The study hypothesized that conflict and attachment would remain stable over time even in the face of taking on caregiving responsibilities. This hypothesis was supported at both wave I and wave II with stable attachment and conflict scores. According to Pohl, mother-daughter attachment scores were reported above the middle range of the scale indicating that daughters perceived themselves as attached but not excessively so.

Summary

Caregiving by daughters for elderly mothers is a unique experience for women. Adult daughters experience more stress when compared with sons in caregiving situations (Horowitz, 1985). Caregiving by daughters can be viewed as an extension of the continuum of care by adult daughters for mothers (Walker & Pratt, 1991). The mother-daughter relationship remains stable even in the context of taking on the new caregiving role (Pohl, 1992).

Positive Beliefs About Caregiving

Walker, Shin and Bird (1990) conducted a study that considered perceived changes in the quality of the mother-daughter relationship in the context of caregiving. It was predicted that the actual experience of caregiving would be related to the perception of a relationship change with some daughters experiencing a positive change while others perceived no change or a negative change or no impact. Perceptions among daughters of positive relationship changes were hypothesized to be associated with awareness of the benefits derived from the caregiving role, and perceptions of negative relationship associated with awareness of the cost of caregiving.

The sample consisted of one hundred thirty three mother-adult daughter pairs who volunteered for the study. All the pairs were white with the exception of one pair who identified themselves as Native Americans. Data was collected by means of two interviews about two months apart with each member of the pair being interviewed separately. Daughters who had longer interviews than mothers were paid $20 for participating.

A total of six measurement tools were used in this study. Satisfaction with caregiving was measured using a domain satisfaction scale developed and validated by Campbell, Converse, and Rodgers (1976). The scale consisted of ten semantic differential pairs with a likert type scale of one through seven. Relationship quality was measured by a seventeen item likert type intimacy scale developed by Walker and Thompson (1983). Specific construct validity was not given for this scale. Perceived caregiving/care receiving of the relationship was developed for this study and consisted of a one item question with a open ended follow-up of why. Degree of bother and difficulty providing care and quality of care provided were single item questions used to measure the construct. No information on source of the questions or reliability was given. Care needed was assessed by respondents responses within eight categories of instrumental aide and then a mean level of the mother's dependence was calculated. Scores were also evaluated to assess the number of areas in which care was provided.

Half of the daughters (50.4%) perceived that the caregiving situation had a positive impact on their relationships with their mothers while 44.2% perceived no change and 5.4% perceived a negative impact on the relationship. The positive impact of caregiving was related to the greater amount of time spent with mothers, more understanding in the relationship, and the act of providing care demonstrates care. The negative impact of caregiving reported by daughters included feelings of resentment for having to do it, feeling obligated, and the demands placed on the daughter by the mother. Analyses of variance with daughter's perceived effect on the relationship as the grouping variable and the daughters' caregiving satisfaction as dependent variables were done. "Perceptions of relationship change were related to overall satisfaction with caregiving in that daughters who perceived negative change had more negative evaluations of caregiving than daughters who reported either positive or no change" (Walker, 1990, p. 149). Daughters who reported that their relationships worsened as a result of caregiving reported significantly lower intimacy scores in comparison with those who reported no change or positive effects. Intimacy was significantly correlated with perceptions of relationship quality and perceptions of relationship closeness.

Limitations of this study include the question of the reliability and validity of the measurements used as no specific evidence was given. Three of the scales were

limited to single item questions which could limit the ability to obtain information. The sample was also a limitation of the study as it consisted of individuals who volunteered for the study which may have an effect on the positive results obtained as well as ability to generalize to the general public. In this study, only 29% of the mothers required personal care which may have had an effect on the study results. In addition, none of the care receivers suffered from dementia which may also impact the findings.

Wood (1991) reported on a qualitative research project whose purpose was to describe the experiences of caregivers who were providing care to an individual who had been recently discharged from a physical rehabilitation program. The study consisted of ten subjects who had been discharged within the past two months from a rehabilitation program in the southeastern United States. Of the ten subjects, three were wives, two were daughters, one each of granddaughter, daughter in law, mother, son and husband. The method of data collection was a semi-structured interview conducted in the subject's residence. Data was recorded on audiotape and later analyzed by identifying themes within the transcribed tapes and coding according to categories established during data analysis. Themes identified by the researchers included attitudes toward caregiving, changes brought on by caregiving, experience and assistance with caregiving,

information on how the caregivers cared for themselves as well as positive and negative experiences of caregiving.

Positive themes expressed by the caregivers included a sense of fulfillment in knowing they were putting forth their best effort in assisting loved ones as well as developing an appreciation for life in general.

Strengths of a qualitative study include the ability to identify themes important to the individual being interviewed. Limitations of the study include the size as well as the non random sample which limit the generalization to the general population.

Archbold, Stewart, Greenlick, and Harvath (1990) studied mutuality and preparedness as predictors of caregiver role strain. Mutuality refers to the caregiver's ability to find gratification in the relationship and meaning in the caregiving situation and the caregiver's ability to perceive the care receiver as reciprocating by their existence. Preparedness refers to the readiness to take on the caregiving role.

The sample for the study consisted of seventy eight dyads who participated in six week and nine month post hospitalization interviews. All care receivers were sixty five years or older and belonged to a large HMO in the pacific Northwest. Care receivers had to require assistance in one or more of the following: a) medications or injections; b) bathing, shampooing, or dressing; c) walking, shopping, or errands; or d) household chores such as

cleaning. Caregivers had to be over eighteen and speak English. Caregivers consisted of wives (19%), husbands (26%), daughters (21%), sons (6%), daughter's in law (13%), other relatives (10%), or friends (5%).

Measures used for the study included the "Family Caregiving Inventory" (Archbold & Steward, 1986) which consist of separate structured interviews for caregivers and care recipients lasting two hours and one hour respectively. Measures of seven predictor variables and nine measures of caregiver role strain are included in the inventory. Alpha coefficients were reported at greater than 0.70 for nine out of ten predictors and outcomes reported in the study.

Multiple regressions were used to test the hypothesis. After controlling for five variables commonly found to be predictors of caregiver role strain, mutuality and preparedness were associated with lower levels of caregiver strain except in areas associated with strain from economic burden, worry, and lack of resources. Strain from direct care, increased tension, and global strain appeared to be affected by higher levels of mutuality and preparedness.

Limitations of the study included the large number of regression analysis and the relatively small sample size as well as the inability to generalize to the general population because of convenience sampling.

The Pohl (1992) study which was previously described looked at affective commitment to caregiving which included positive and negative beliefs about caregiving. Positive

beliefs were measures by the Self-Esteem Scale (Given, Given, Stommel, Collins, King, & Franklin, 1992) which was a seven item scale which described positive beliefs about caregiving. (See methods section for detailed instrument description.)

The study hypothesized that mother-daughter attachment would directly predict positive beliefs about caregiving. This hypothesis was supported at Wave I but results were questionable at Wave II. There was no significant change in positive beliefs between Wave I and Wave II. According to Pohl, daughters reported moderately high positive beliefs about caregiving.

Qualitative findings supported the quantitative results. Positive beliefs about caregiving included items such as feeling good about caring for mother, or finding it rewarding or fun.

A major strength of this study was the qualitative portion which supported the quantitative data.

Summary

Positive beliefs are associated with the caregiving experience. Beliefs include a feeling of a positive impact on the relationship (Walker, Shin, & Bird, 1990), a sense of fulfillment, and an appreciation for life in general (Pohl, 1992; Wood, 1990). Mutuality and preparedness may mediate some of the burden associated with the caregiving role (Archbold et al., 1990).

Negative Beliefs About Caregiving

Walker, Martin, and Jones (1992) conducted a study on benefits and costs of caregiving and receiving for mothers and daughters. The sample consisted of one hundred forty one primarily white (two Native Americans) mother-daughter pairs from rural and urban areas of western Oregon who volunteered for a longitudinal study on mother-daughter relationships. Daughters were included in the study if they provided more than half of transportation, housekeeping, meal preparation, laundry, personal care and/or financial support and had a mother who was cognitively intact, over sixty five and living within forty five miles of the daughter.

Data were collected in face to face interviews primarily in homes. Participants were paid for participation. Demographic data, amount of care, and situational data were collected during the initial interview and costs and benefits were assessed during a second interview approximately two months after the first interview.

Measurement tools used for the interview included the Walker and Thompson Intimacy Scale (1983), information on ADL and IADL assistance, and perception of health. Outcome factors were developed for the study which included Factor 1: Insufficient time (alpha=.86); Factor 2: Frustration (alpha=.82); and Factor 3: Anxiety (alpha=.61). Block regression analysis was done to analyze data with first block consisting mainly of demographic variables to be reflective of background factors prior to the start of caregiving and second block factors reflective of situational factors that affected the caregiving situation.

The results of the study confirmed the cost of the caregiving experience for the caregiving daughters. The data showed that the performance of caregiving tasks led to feelings of frustration while anxiety reflected concern over one's ability to give care. Caregiver duration was an important predictor of anxiety as daughters with shorter caregiving history showed more anxiety. Costs reflecting the impact of caregiving on the caregiver were confirmed. Married daughters reported greater time costs than did single or divorced daughters. Shared living quarters and mother's health were also predictors of increased time costs for the daughters.

Strengths of the study included the statistical procedures used which entered all variables at the same stage in the regression. The size of the sample was good for the amount of information gathered. Limitations of the study included the sample which because of the voluntary participation, limited sampling area, and the lack of representation of ethnic groups limit the ability to generalize findings. Findings from the anxiety outcome should be viewed with caution as the alpha rating on the variable was low.

Sheehan and Nuttall (1988) examined the contributions of interpersonal conflict, affection, caregiver satisfaction, distress concerning dependency as well as objective demands of caregiving in predicting caregiver strain and negative emotion. The sample consisted of ninety eight family caregivers providing care to frail or impaired elderly relatives. The majority of the sample was adult children (n=75) with females making up the majority (83.6%) of the sample.

Data were collected by an initial self-administered questionnaire followed by a four month follow up questionnaire. Personal strain was measured using a six item scale which assessed the degree to which the caregiver felt his/her responsibilities were affecting job performance, financial matters, social or recreational activities, and relationships with others. Negative emotion (adapted from Circirelli, 1981) assessed the degree to which caregivers experienced the following emotions: frustrations, impatience, depression, helplessness, resentfulness, isolation, emotional exhaustion, nervousness, anger, and feelings of incompetence. The Hopkins Symptoms checklist (Derogatis, Lipman, Rickels, Uhlenhuth, and Covi, 1974) was used to create subscales for depression, anxiety, and somatization.

The results of the study supported the concepts that subjective factors are important in explaining the negative consequences of caregiving. Negative emotions were found to be associated with depression, anxiety and somatization. Conflict was also noted to be strongly associated with negative affect.

Limitations of the study include the fact that psychometric data was not presented to support the reliability of the instruments used. The sample was also non-random which may limit the generalization of findings.

Stull, Kosloski, and Kircher (1994) studied the burden variable as a predictor and outcome to determine if it is a legitimate variable for caregiver research. Some previous literature has suggested that burden and well being may be opposite sides of the same coin and that measures of well being may be used to compare caregivers to non-caregivers.

Data was obtained from the Eldercare Project conducted in northeast Ohio. Subjects were self referred in response to advertisements, newspaper stories and mass mailings from the local congressional representative. Screening interviews were done with respondents to determine eligibility. Longer structured interviews were then scheduled with the one hundred eighty nine relatives who identified themselves as primary caregivers.

Caregivers were predominantly female (86%) with the largest group composed of daughters (57%). Two thirds of the elders were women averaging eighty two years old. Approximately half have some type of cognitive impairment, and half need help with six or more (out of thirteen)

ADL/IADL tasks with twenty five percent needing help with eight or more.

Measures for the study were divided into four main categories. Antecedents were described as features of the caregiving situation that are likely to affect caregiver burden or well being. This measure was tapped by a twenty four item scale which included ADL's/IADL's and tasks. Generic well being was measured by assessing caregiver perception of health with a single item question (Alpha Coefficient=0.86), social activities (Alpha Coefficient=0.63), and financial household income which was based on five thousand dollar increments (Alpha Coefficient=0.59). Measures of burden were measured using content areas either explicitly or implicitly implied in previous research. Areas included physical, financial, social/time and interpersonal. Some questions were taken from previous scales and some questions were developed for this project. Three measures of burden, physical (Alpha Coefficient=0.81), social (Alpha Coefficient=0.80), and financial (Alpha Coefficient=0.58), were used in this study. Outcomes that were used as measures in this study include use of community assistive services, utilization of day care, and finally thoughts of nursing home placement.

Correlations and regressions were done to analyze data. Findings suggested that burden is a unique part of the caregiving experience. Burden across all three measures was shown to have larger correlations with the antecedent variables previously described than with the generic variables of well being. Caregiver burden measures were also better predictors of outcomes than were the measures of well being.

The main strength of this study is the ability to compare caregivers with noncaregivers. Limitations include the low alpha coefficients on some of the variables particularly the well being variables which may influence the results.

Stommel, Given, and Given (1990) studied depression as an overriding variable in the caregiver burden variable. This study viewed burden as subjective perception of reactions to the caregiving experience. Predictors of caregiver burden fell into three categories: a) characteristics of the patient; b) characteristics of the caregiving situation; and c) characteristics of the caregiver.

The sample for this study involved three hundred seven caregivers who were part of a longitudinal study involving patient dyads from one hundred forty five community agencies in the Midwest who identified family members who cared for dependent elderly relatives in their homes. The primary caregivers were interviewed in their homes and were the exclusive source of information for the dyad.

Measures used for the study included the following instruments. A new tool was developed that consisted of twenty seven items which formed five subscales measuring

perceived caregiver burdens including impact on finances, impact on health, impact on schedule, feelings of being abandoned by family and sense of entrapment. The Alpha Coefficients ranged from 0.72 to 0.87 in the sample. The scale developed was tested on a pilot sample of ninety nine, redesigned to include seventy seven items which were administered to the present sample with the final measure consisting of the twenty seven items described above.

Involvement in patient care was measured by asking caregivers if care recipients were dependent in any of twenty seven areas which included ADL's, IADL's as well as selected medical tasks. Frequency of task was also assessed using a scale which ranged from no involvement to several times a day.

Informal support was measured by assessing assistance and relief provided by others to the caregiver and total number of persons available for help. Formal support/service utilization was assessed by measuring the following: a) number of visits to a physician/ER during the three months prior to interview; b) all instances of community service use during the three month period prior to the interview; and c) number of days the care recipient spent in a hospital, nursing home or rehabilitation center.

Financial situation was assessed by gathering data on out-of-pocket expenditures during the six month period prior to the interview and included items such as recipients medication, assistive devices and formal services.

Patient characteristics were measured by health indicators of patient physical and mental health. Cognitive behavior was measured by a six item four point likert type scale developed by Given and Given (1989) which was confirmed by independent samples of Alzheimer's patients.

Caregiver depression was measured using the Center for Epidemiologic Studies Depression Scale (CES-D) (Radloff, 1977) which has been widely used especially in studies focusing on depression in non psychiatric populations. The Alpha Coefficient was 0.89 for this sample.

Statistical procedures used in the study were bivariate correlations between the burden variables and the independent variables described previously. High correlations were consistently found between the burden variables and the CES-Depression Scale. Hierarchical multiple regression were carried out to assess the relative impact of depression and the process variables affected different dimensions of burden. The sense of entrapment subscale (negative beliefs) used in this study appeared to be affected by many of the process variables although the connection was weak. The process variable "others involved in patient care" appeared consistently to reduce the caregiver sense of burden in feelings of abandonment, impact on schedule, and sense of entrapment burden scales.

Overall, this was a well designed study. Measures used appeared to be statistically reliable. The study looked at caregiver burden from a variety of views.

Limitations include the non random sampling which limit the ability to generalize to the general population. Information was obtained only from the view of the caregiver which may influence results.

Barnes, Given, and Given (1992) studied caregivers of the elderly including spouses of adult children. This study consisted of two hundred and six primary caregivers who were participants in a larger longitudinal study of three hundred and seven family members described previously. The study looked at four distinct groups to determine differences in caregiving. Groups consisted of a) spouse caregivers who have children (n=114); b) spouse caregivers who have no children (n=13); c) adult child caregivers who have siblings (n=55); and d) adult children caregivers who have no siblings (n=24). Adult children caregivers were mainly daughters (n=70, 89%). Community public health and home agencies recruited caregivers by distributing a single page description of the study with a self-addressed stamped postcard used for recruitment of subjects. Criteria for inclusion in the study included the care recipient had to be over sixty four, be dependent in two or more self care activities and the family member had to be acknowledged as the primary caregiver. Trained interviewers using a written script conducted phone interviews with the caregivers.

Twelve measures were used in this study including six measures assessing caregivers perception of burden as follows: a) financial impact of caring (Alpha

Coefficient=.72); b) impact of caring on caregivers health (Alpha Coefficient=.85); c) impact of caring on schedule (Alpha Coefficient=.81); d) feelings of family abandonment (Alpha Coefficient=.87); e) role responsibility scale (Alpha Coefficient=.80); and f) negative reaction to caregiving (Alpha Coefficient=.78). Measurements of caregiving involvement including: a) ADL (Alpha Coefficient=.90); b) IADL (Alpha Coefficient=.78); c) affective social support (Alpha Coefficient=.88); d) mental health status including positive well being scale (Alpha Coefficient=.92); e) Center for Epidemiologic Studies Depression Scale (Alpha Coefficient=.88); and f) use of community services were measured.

A repeated measure of analysis of variance with the various groups of independent variables was conducted for each of the twelve dependent measures.

Child caregivers reported greater feelings of abandonment when compared to other groups with child caregivers with siblings reporting the greatest feelings of abandonment than those without siblings. Child caregivers with siblings also reported a greater negative reaction to caregiving than those without siblings. Caregivers as a group reported negative impact on health, expressed receiving less affective support, and all expressed feelings of abandonment over time.

This was a well designed study with multiple measures of the impact of burden. Limitations include the non random sample with the inability to generalize to the general population.

The Pohl (1992) study which was previously described also studied negative beliefs as part of the affective commitment to caregiving. Negative beliefs were measured on a seven item "sense of entrapment" developed by Stommel, Given, and Given (1990). (See methods section for complete scale description.)

The hypothesis for this study was that mother-daughter conflict would predict negative beliefs about caregiving. This finding was supported at both Wave I and Wave II of the study. Daughters in this study express moderate negative beliefs about caregiving. Negative beliefs were also positively correlated to "remains in care" as an outcome.

The qualitative portion of the study confirmed the negative aspects of caregiving by such statements as feeling study with the job; resentment toward family members for not helping; and lack of freedom and worry which were expressed by the caregiving daughters.

Summary

Negative beliefs are widely discussed in the literature. Burden is a legitimate variable in the caregiving experience. Negative beliefs associated with caregiving include feelings of frustration and anxiety related to the caregiving situation. In addition, there are high costs of time associated with caregiving (Walker et al., 1992). Feelings of depression and abandonment accompany the role (Barnes et al., 1992; Stommel et al., 1990).

Family Support

In addressing the family social support literature, very little information can be found that addresses social support from strict family support view and does not include all sources of support. Brody, Hoffman, Kleban, and Schoonover (1989) studied caregiving daughters and local siblings to examine perceptions of caregiving, strains associated with caregiving and the interaction among siblings relating to caregiving.

The sample consisted of seventy-one families in which the daughter caregiver had a local sibling. The data obtained for the study was obtained through structured interview with the caregiving daughters and a local sibling. Fifty-eight percent of the siblings were females and 42 percent males. Subjects were recruited from a previous study on filial caregiving as well as new subjects who were recruited to increase the sample size.

There were a total of five instruments used for this study including two new instruments which were developed to examine the problematic and rewarding aspects of the parent care situation. These included Intersibling Parent Care Hassles consisting of 25 negative interactions pertaining to caregiving that may occur and a list of 12 Intersibling Parent Care Uplifts. Items were also developed to evaluate family interactions including satisfaction of the relationship with mother and the closeness of current sibling and family relationships.

Groups were analyzed separately, caregiver, sister, brother, by using one way analysis of variance. Hassles and uplifts were analyzed by frequency tests; critical ratio, factor analysis and regression models.

Caregivers exceed both groups of their siblings in perceived shortcomings in the way their siblings were meeting parent care responsibilities. In reporting the results, Brody et al. (1989) state, "The importance to primary caregivers of socioemotional support is amply apparent. They were candid in expressing resentment that their siblings were doing less parent care. They also were the group most distressed by siblings failure to give them emotional support and by more active negative behaviors such as being critical of their efforts. Conversely, the caregivers felt rewarded when siblings did give emotional support and understood their efforts for the parents" (p. 537).

Gender differences in the caregiving sisters were also reported in the caregiving siblings with the sisters expressing more discomfort over the role of the secondary caregiver, feeling guilty about not being able to do enough. The sisters did appreciate when their efforts were recognized.

Brothers were the group least affected by the caregiving situation. They reported providing the least

instrumental and emotional help and having their own emotional and physical health least affected. The brothers reported the least intersibling hassles.

Overall, this was a very comprehensive study which made an attempt to study the relationship of family in the caregiving situation. Strengths of the study included a large sample size and very comprehensive information obtained from the participants. Data was subjected to vigorous statistical analysis. A limitation of the study was the lack of reliability information on the instruments that were used. Little information was included on the new instruments developed specifically for this study. The sample used in the study was non random which limits its ability to be generalized to the general population.

Zarit, Reever, and Bach-Peterson (1980) first introduced the concept of providing support to caregivers as a critical step in the community care of the elderly with dementia. The study examined how caregivers are affected by care of a dementia patient in the home as well as the effects of social factors such as formal and informal support to the care receivers.

The sample of this study consisted of 29 elderly dementia patients and their 29 primary caregivers. Primary caregivers consisted of 25 females and 4 males with 18 being spouses and 11 daughters. Subjects were recruited from a research and training center which offered counseling and memory training to older persons.

This was a descriptive study and data was gathered by interviews which took place in the subject's homes and lasted about one and one-half hours. Several tools were used to gather data about burden and caregivers were also asked about the frequency of visits of other family members to the dementia patient and if any social or health services were being provided.

In the findings, the frequency of family visits was significantly related to the level of burden indicating that older persons receiving more visits from children, grandchildren, and siblings had caregivers who reported less burden.

Limitations of the study included the small non random sample. Information was not elicited on what assistance the visitors offered or the quality of the visits which may affect the degree of relief the caregiver receives.

George and Gwyther (1986) studied caregiver well-being by examining the impact of caregiving on four generic categories of well-being which included physical health, mental health, social participation and financial resources. The sample of the study (n=510) consisted of family caregivers from the mailing list of Duke University Family Support program and represented an 89% return of the questionnaire instruments. The sample consisted of spouses, adult children and friends and was composed of 71 percent women.

Eligibility criteria for inclusion in the sample required only that the caregiver by providing some level of care to a memory-impaired adult. Care ranged from living with the individual to providing care to an institutionalized older adult. This study compared the results of the caregivers with a comparable group of community members.

Social participation was measured using both objective and subjective indicators. Each objective measure was accompanied by a subjective assessment of the caregivers satisfaction with the frequency and quality of social/recreational activity. Perceived need for social support was measured by a single item question. Fifty-nine percent of the sample expressed the need for more support while 41 percent indicated adequate social support. Groups were compared by t-tests on the basis of need for social support. Results indicated that "those caregivers who do not need more social support report higher well-being than those who desire more assistance from their friends and kin" (p. 258).

Strengths of this study included the size of the sample and the high return rate of questionnaires. Limitations of this study include the use of a single question to measure need for social support. Another limiting factor may be the wide variety of care situations represented in the sample as previously described. Non random sampling and the use of one geographic area limit the ability to predict results in other groups.

Ballie, Norbeck, and Barnes (1988) investigated the effects of perceived caregiver stress and social support on the psychological distress of family caregivers of the elderly. The study proposed the following three hypothesis:

1. Perceived stress of caregiving will be positively related to psychological distress (partially supported).
2. Satisfaction with social support will be negatively related to psychological distress (supported).
3. Social support will have a buffering effect on the relationship between perceived caregiver stress and psychological distress (not supported).

The sample for the study was 87 caregivers recruited and tested an initial meeting of educational groups sponsored by a county health department. The group included spouses (18.4%), adult child (48.3%), other relative (25.3%), and friends (8.0%).

The study was a descriptive study that used self-report questionnaires that were completed in one sitting and required 30 to 45 minutes to complete. Two of the scales used in this study were designed specifically for this study and pretested in a pilot test. The Perceived Stress Scale consisted of 16 items and had an Alpha Coefficient of 0.90. The Satisfaction with Social Support Scale consisted of 8 items and had an Alpha Coefficient of 0.84. Psychological distress was measured by a "Profile of Mood States" by McNair, Lorr, and Droppleman and for this study had a 0.89 Alpha Coefficient.

This study used correlations and multiple regressions to study the variables. The ability of perceived stress and satisfaction with social support to predict psychological distress and depression were initially supported but when more specific caregiver demands were included in the regression, the perceived stress could not be supported. The role of social support in predicting psychological distress was supported but no evidence could be found to support a buffering effect of social support.

Strengths of this study include the statistical methods that were used to test the hypotheses. Weakness of this study include the introduction of two new scales which the researcher attempted to overcome by the use of pilot studies. The sample was also very limited in size and non random.

Strawbridge and Wallhagen (1991) looked at conflict among family members and its effect on the caregiving role. Conflict was measured on a social support scale which was designed to measure the negative aspects of social support. The aims of the study were to quantify the extent of family conflict among adult children caregivers and to analyze its impact on caregiver perceived burden and mental health when compared to other variables.

The sample for the study was one hundred adult caregivers caring for frail parents or in-laws recruited from eight organizational sites including adult day health centers, home health agencies, and informational and referral agencies in Northwestern Washington and the San Francisco Bay area. The sample was 83 percent female with 73 percent of the sample considered to be the primary caregiver.

The study was a descriptive study which used a structured interview technique which took place in the subjects' home or place of employment and took approximately one hour to complete. Structured interviews were used to measure family conflict, perceived burden, caregiver tasks, caregiver mental health, relationship quality with parent, care preferred for self, and income.

Chi Square and t-tests (2 tailed) were first used to compare the differences between caregivers experiencing conflict and those not experiencing conflict. Path Analysis was then used to analyze causal paths and compare other variables.

Fifty-eight of the caregivers reported a family member as somewhat or very upsetting on the social support scale. Of these, eighteen on further investigation indicated the problem to be relatively minor leaving forty caregivers as experiencing family conflict. The three main causes of conflict included the relative not providing sufficient help for the care receiver (60%), criticizing what the caregiver was doing (12.5%), or insisting the care recipient be institutionalized (10%). In 80 percent of the cases, the conflict had been recent. "Family conflict had a significant impact on caregiver perceived burden and mental health, results that remained even when relationship quality with the parent, caregiver tasks, caregiver income, gender, and age were taken into account" (p. 775).

Strengths of the study include the wider geographic area and variety of sources for subjects. Statistical analysis were strong utilizing path analysis. Limitations of the study include the subjects which were predominantly from middle and upper socioeconomic groups. Generalization to the general public should be made with caution.

Clipp and George (1990) studied social support by analyzing dimensions which included an objective measure of instrumental assistance received and a subjective measure of the caregiver's perceived adequacy of social support received from family and friends and how the measures changed over time.

The population in the study was from the Duke University Family Support Program which was described in Gwyther and George (1986). This study compares data obtained in phase two of the study and consists of the 510 subjects from phase one to the 376 who returned questionnaires in phase two of the study which took place on year after the initial study.

The instrumental assistance scale for this study is a multi-item scale on which respondents were asked to rate the following types of assistance from (0) "never" to (4) "regularly". Specific indicators for the types of assistance include help when sick, help with shopping or running errands, help with money or bills, help with household repairs, help with housework, financial or business advice, companionship, advice about problems, transportation, and help with meals. The mean score for instrumental support at time one and time two were 15.92 and 19.5 with higher scores indicating more support. The increase suggests caregivers receive more help over time although absolute levels of assistance remain low.

The instrumental questions were followed by a subjective question indicating if the caregiver perceives the need for more social support. During the one year time interval, the perceived need for social support increased from 57 to 62 percent. No correlation was found between the measures of objective and subjective social support.

Strengths of the study included the relatively large sample size at both Phase One and Phase Two. Limitations of the study include the short interval between measures indicating an ability to observe only short term changes. The authors also identified the need to measure social support in greater than a two dimensional scale as well as a method to measure perceived adequacy with greater than a one question measure. As previously discussed, the limitations of the population due to demographics may have affected the outcome of the study.

Summary

Very little information can be found in the literature that addresses social support from a strict family point of view. Brody, Hoffman, Kleban, and Schoonover (1989) study, did point out the need for increased socioemotional support by family members to caregiving daughters.

Social support did seem to have a positive impact on the caregiving situation with caregivers reporting less burden associated with increased visits (Zarit, Reever, & Bach-Peterson, 1980), increased instrumental support over time, (Clipp & George, 1990), satisfaction with social support being related to less psychological distress (Ballie, Norbeck, & Barnes, 1988).

It is apparent from the literature review that daughters have a unique perspective on caregiving. Negative and positive feelings are both present in the caregiving experience. Social support may help to alleviate some of the burdens associated with caregiving. The purpose of this study is to look specifically at family support for a correlation with negative and positive feelings about caregiving in hopes of adding to the body of knowledge about the caregiving experience.

METHODOLOGY

Overview

In this research study, the perception of family support is explored in relationship to positive and negative feelings about caregiving among a group of daughters caring for their elderly mothers. The purpose of this chapter is to explain the research methodologies and design. A description of the variables, the operational definitions, the study sample, the data collection methods, analysis plan, and procedures used for the protection of human subjects is presented.

Basic design

The basic design of this study is a descriptive correlational study of the perception of family support and positive and negative feelings about caregiving among a group of daughters caring for their elderly mothers post hospitalization. The design is non-experimental.

Operational Definitions

Positive feelings about caregiving describe positive adaptation to the caregiving situation including feelings of enjoyment, satisfaction, and willingness to care for mother. The operational definition is the mean score on the self esteem scale items number 4, 8, 9, 13, 17, 26, and 32 from the caregiving inventory located in Appendix A taken from the Caregiver Reaction Assessment tool (Given, Given, Stommel, Collins, King, & Franklin, 1992).

Negative beliefs about caregiving describe negative ineffective responses to the caregiving situation such as feelings of discouragement, entrapment, and resentment in caring for mother. The operational definition is the mean score on the sense of entrapment sub-scale consisting of item numbers 6, 21, 27, 30, 33, 36, and 39 from the caregiver inventory located in Appendix A taken from the Caregiver Burden Inventory (Stommel, Given, & Given, 1990).

Family support describes the caregiver's perception of the family's willingness to help, spend time with mother, offer emotional support to the caregiver, and work with the caregiver as needed. The operational definition of family support is the mean score on items A through H on the Social Assistance Scale found in Appendix A developed by King and Barnes (1990). Alpha Coefficient correlation will be performed to confirm the reliability of the scale.

Selection of Subjects

The sample for this study came from a large study conducted at Michigan State University (MSU) entitled, "Caregiver Responses to Managing Elderly Patients at Home" and funded by the National Institute on Aging (R01 AG06584-06, Given, 1988). The study consisted of 1,038 first time family caregivers from 27 hospitals and vising nurse associations in Michigan. The agencies represented urban as well as smaller community areas. Patients in the study had a broad range of medical diagnoses. Discharge planners as well as graduate medical students were used to recruit families for the study. The purpose of the larger study was to examine family caregivers who were experiencing new dependencies in the caregiving role over an eighteen month period of time. Six hundred twenty-eight caregivers agreed to participate and met the criteria for the larger study.

This project utilizes a subset of the above sample (n=120) consisting of daughters new to the caregiving role identified by Pohl (1992). The goal of this project is to look at the effect of perceived family support on positive and negative beliefs about caregiving in this subset. Inclusion criteria were set by Pohl (1992) and included the following: 1) daughter was the primary caregiver of the mother for the first time; 2) mother was 55 or older; 3) daughter was assisting with at least one ADL or two IADL's or one health care activity; 4) the mother resided in a home in the community (either own home or a family member's or friends'); 5) daughter was not paid for caregiving; 6) daughter was not caring for more than one disabled family member when the study began; and 7) daughter spoke and read English.

Instrumentation

Positive beliefs about caregiving was measured by using a seven item scale labeled "self esteem" on the Caregiver Reaction Assessment (Given et al., 1992). The scale describes positive reactions to caregiving such as enjoy caring for mother, feel privileged to care for mother, really want to care for mother, etc. Responses to each item range from one (strongly disagree) to five (strongly agree). Item number 9 "I wish my family depended on me less to care for ________." is reverse scored item. A higher score indicates more positive beliefs about caregiving. Mean scores, ranges and standard deviation will be used. The overall scale has been subjected to rigorous testing including confirmatory factor analysis. Cronbach's alpha for this scale has been reported .90 (Given et al., 1992) on a mixed population and .80 (Pohl, 1992) which consisted of daughters only.

Negative beliefs about caregiving were measured using a seven item sub-scale labeled "sense of entrapment" which described negative feelings about caregiving (Stommel, Given, & Given, 1990). The seven items included items like feeling overwhelmed by problems, getting discouraged, feeling forced into caring for mother, etc. and were part of a forty-two item caregiver burden inventory. The scale was subjected to vigorous testing by the authors. Responses on the scale range from one (strongly disagree) to five (strongly agree). A higher score indicates more negative beliefs about caregiving. Mean scores, ranges, and standard deviation will be used. Cronbach's alpha were reported at .88 both the Pohl (1992) daughter sample and from a mixed sample (Stommel et al., 1990).

Family support was measured by the Social Assistance Scale. This is an eight item scale which describes different type of assistance offered by family members such as staying with mother so caregiver could do something else, helping with transportation, checking on caregiver to be sure you are all right, helping with physical care, etc. Responses on the scale range from one (rarely or none of the time) to four (almost all of the time). A higher score indicates more family assistance. Mean scores, ranges, and standard deviation will be used. Reliability for this scale is not available so inter-factor correlation will be done to confirm reliability for this scale.

Demographic data will also be used to describe characteristics of the group including race, caregiver marital status, caregiver educational level, caregiver employment, mother's marital status, mother's living arrangement, number of assistance required by mother with ADL, IADL and health activities. Caregiver's perception of mother's overall physical and mental health will be included for descriptive purposes.

Data Collection Methods

Data for this project includes information obtained during the initial screening interview used to determine eligibility as well as information obtained during a follow-up interview and questionnaire. Data was collected by discharge planners and medical students who underwent vigorous training which included instruction as well as role playing and practice videotaped interviews. Initial screening interviews of the daughters involved in the study occurred within two to four weeks (n=21 days) after the mother was discharged from the hospital. The screening interview assessed whether the caregiver situation met the criteria for the study was well as the mother's limitation. The follow up interview was to have occurred within one month of the screening with the mean time range between screening and follow up being 21 days.

This project is a secondary analysis of data that was obtained for the larger MSU study and consisted of the initial telephone screening interview, the follow up interview lasting forty-five to sixty minutes and followed by the paper and pencil self-completed questionnaire which respondents returned by mail.

Analysis of the Data

Quantitative data analysis will be carried out using a "Pearson r" formula to look for correlations among the study variables. A significance level of .05 will be used for the project. The independent study variables are positive feelings about caregiving and negative feelings about caregiving. The independent variable is family support.

Demographic data will be summarized including the mean, the standard deviation of the following variables including race, marital status of caregiver, educational level of caregiver, employment status of caregiver, marital status of mother, number of assistance required with ADL, IADL, and health activities, and living arrangement by category. Demographic data will be used for descriptive purposes to describe the population.

Protection of Human Subjects and Approval

The subjects involved in the larger study gave written consent after the study was explained in person and in writing when they were recruited. The larger project was approved by the University Committee on Research Involving Human Subjects at Michigan State University and each of the twenty-seven agencies recruiting subjects. The caregiver and patient were given a letter of explanation with a toll free 1-800 number they could call if they had questions or concerns regarding the study. There were no identified risks to the caregiver in the primary study. The main concern identified was the time commitment which included the forty-five to sixty minute telephone screening interview and the follow up questionnaires expected to take approximately twenty minutes to complete. Confidentiality was provided by the use of case numbers versus names on all questionnaires.

The present project involves the secondary analysis of data obtained from the larger study. The project was reviewed by and received approval from the University Committee on Research Involving Human Subjects (UCRIHS) at Michigan State University prior to data analysis. Formal approval can be found in Appendix B located in the back of the study. The researcher had access to data case numbers only to maintain confidentiality. The researcher received the data by case number on a disk with no identifying information which prevented the investigator from identifying any individuals participated in the study.

Assumptions and Limitations

1. A secondary analysis of data limits the researcher to information obtained by the initial researcher.
2. Persons who voluntarily participate in studies may not be representative of the population which will limit generalization to the population as a whole.
3. Not all biases can be accounted for in a small study.
4. Daughters offer a unique perspective and response to the caregiving role.
5. The Social Assistance subscale is a newly developed scale and psychometrics are not available.

Hypotheses

The following hypotheses are proposed for the study:

1. Family support will be positively related to positive beliefs about caregiving.
2. Family support will be negatively related to negative beliefs about caregiving.

RESULTS

This section includes a description of the data analysis. Tables are provided to summarize the data and to address the research question of: **Among a group of caregiving daughters providing care to elderly mothers, is there a relationship between the perception of family support for the caregiving role and positive and negative beliefs about caregiving?**

Sample

This analysis consists of 120 daughters caring for their elderly mothers post hospitalization. Caregiving daughters were primarily Caucasian (n=102, 85%) with African American (n=13, 10.8%), Mexican American (n=2, 1.7%), Native American (n=2, 1.7%), and Asian/Pacific Island (n=1, 0.8%) making up the remainder of the sample. The majority of daughters were married or remarried (n=20, 16.7%), with single, never married (n=20, 16.7%) or divorced (n=14, 11.7%) making up the remainder of the population. Educational levels varied from grade school or less (n=1, 0.8%) to graduate professional degree (n=5, 4.2%), with the majority of daughters reporting high school (n=37, 30.8%), some high school (n=21, 17.5%), or some college or technical education (n=44, 36.7%). The majority of daughters (n=79, 65.8%) reported being employed outside the home prior to caregiving with the majority (n=57, 47.5%) reporting full time employment. At the time of data collection, full time employment had dropped (n=39, 32.5%) with daughters (n=3, 2.5%) quitting work for caregiving, and daughters (n=2, 1.7%) on a leave of absence from employment.

The majority of care recipients were widowed (n=94, 78.3%), with married (n=12, 10%), divorced (n=9, 7.5%), separated (n=4, 3.3%), or single (n=1, 0.8%) making up the remainder of the population. Slightly over one half (n=66, 55%), lived with the caregiver (See Table 1). Physical health of care recipients was reported as fair (n=49, 40.8%)

Table 1

Social Demographics - Caregiver and Care Recipient (n=120)

	Frequency	Percent
Caregiver		
Race		
Caucasian	102	85.0
African American	13	10.8
Mexican American	2	1.7
Native American	2	1.7
Asian/Pacific Island	1	0.8
		100%
Marital Status		
Single, Never Married	20	16.7
Married/Remarried	78	65.0
Divorced	14	11.7
Widowed	6	5.0
Separated	2	1.7
		100%
Education		
Grade School or less	1	0.8
Some High School	21	17.5
High School	37	30.8
Some College/Technical	44	36.7
College	9	7.5
Some Graduate/Professional School	3	2.5
Graduate/Professional Degree	5	4.2
		100%
Employment (prior to Caregiving)		
Full Time	57	47.5
Part Time	21	17.5
Employment Status (after taking on caregiver role)		
Employed Full Time	39	32.5
Employed Part Ttime	18	15.0
Self Employed	6	5.0
Retired	17	14.2
Leave of Absence	2	1.7
Unemployed-Layoff	16	13.3
Not Employed for Pay	19	15.8
Quit Work to Care	3	2.5
		100%

Table 1 (cont.)

	Frequency	Percent
Care Recipient		
Marital Status		
Single/Married	1	0.8
Married/Remarried	12	10.0
Divorced	9	7.5
Widowed	94	78.3
Separated	4	3.3
		100%
Living Arrangement		
Live with Caregiver	66	55.0
Live Elsewhere	54	45.0
		100%

to poor (n=47, 39.2%) by caregivers while mental health of the recipient was rated as good (n=57, 47.5%) to fair (n=39, 32.5%) (Table 2).

Table 2

Frequency and Percent of Overall Physical and Mental Health of Care Recipient (n=120)

	Frequency	Percent
Physical Health		
Excellent	2	1.7
Good	22	18.3
Fair	49	40.8
Poor	47	39.2
		100%
Mental Health		
Excellent	4	3.3
Good	57	47.5
Fair	39	32.5
Poor	20	16.7
		100%

Caregiver daughters reported on assistance with activities of daily living (ADL's), instrumental activities of daily living (IADL's), and health care activities (HCA) which were required by the elderly mothers. Activities were scored as independent (needing no assistance) to requiring assistance which ranged from some help/supervision to total assistance (Table 3). See Table 4 for the breakdown by category of the number of assistance with ADL, IADL, and health care activities required by mothers.

Family Support

Family social support was measured by the mean score of the Social Assistance Scale (Barnes & King, 1990). This scale was a new scale used in this study, therefore no reliability and validity data is available for this scale. A correlation matrix was calculated to analyze correlations between items (Table 5). The alpha coefficient was calculated at 0.76 for this scale. Items of the Social Assistance scale were scored on the following scale: 1=rarely or none of the time; 2=some of the time; 3=most of the time; and 4= almost all of the time. The mean scale score for the social assistance scale was 1.79 with a standard deviation of 0.55. Individual item means were calculated as well as mean score for the entire scale. Mean ranges on the scale were minimum 1.00 and maximum 3.75 (See Table 6).

Table 3

Frequency and Percent of Activities of Daily Living, Instrumental Activities of Daily Living, and Health Care Activities Required by Elderly Mothers (n=120)

	Frequency	Percent
ADL's (Needs Assistance)		
Dressing	65	54.2
Eating	30	25.0
Bathing	78	65.0
Walking in house	58	48.3
Toileting	45	37.5
Transferring	48	39.5
IADL's (Needs Assistance)		
Cooking	102	85.0
Housework	114	95.0
Shopping	115	95.8
Laundry	107	89.1
Transportation	118	98.3
Money Management	84	69.7
Health Care Activities (Needs Assistance)		
Urinary Catheter	12	10.0
Oxygen	25	20.8
IV Meds	8	6.7
Tube Feedings	6	5.0
Injections	19	15.8
Exercises	47	39.2
Bedsores	14	11.7
Skin Problems	36	30.0
Colostomy	5	4.2
Post Op Incision	21	17.5
Oral Meds	111	92.5
N-G Tube	3	2.5
Urine Incontinence	26	21.7
Stool Incontinence	27	22.5
Suctioning	3	2.5

Table 4

Frequency and Percent of Dependencies of Activities of Daily Living, Instrumental Activities of Daily Living and Health Care Activities (n=120)

Number	Frequency	Percent
ADL's		
0	28	23.3
1	19	15.8
2	16	13.3
3	10	8.3
4	14	11.7
5	12	10.0
6	21	17.5
		99.9%
IADL's		
0	1	0.8
1	1	0.8
2	3	2.5
3	3	2.5
4	11	9.2
5	29	24.2
6	72	60.0
		100%
HCA		
0	1	0.8
1	27	22.5
2	27	22.5
3	21	17.5
4	19	15.8
5	12	10.0
6	4	3.3
7	5	4.2
8	4	3.3
		99.9%

Activities of Daily Living: M=2.69; SD=2.21
Instrumental Activities of Daily Living: M=5.31; SD=1.13
Health Care Activities: M=3.09; SD=1.89

Table 5

Correlation Matrix - Social Assistance (Family Support)

	Item 1	Item 2	Item 3	Item 4	Item 5	Item 6	Item 7	Item 8
1. Help with physical care	1.000							
2. Spent time keeping company	.5616	1.000						
3. Stayed with mother	.3821	.3807	1.000					
4. Gave daughter emotional support	.3666	.3821	.3807	1.000				
5. Helped with transportation	.2954	.3708	.2978	.2881	1.000			
6. Helped with material goods	.2604	.3280	.4529	.2489	.5132	1.000		
7. Checked on daughter	.0750	.2077	.1797	.4018	.2685	.1926	1.000	
8. Encouraged daughter	.1323	.1331	.3172	.2513	.0198	.0228	.2415	1.000

Alpha Coefficient = .7563

Mean	Standard Deviation	Minimum	Maximum
1.79	.55	1.00	3.75

Table 6

Item Mean Score on Social Assistance Scale (n=120)

	Mean	Standard Deviation
Item 1: Helped with physical care	1.79	.92
Item 2: Spent time keeping mother company	2.19	.96
Item 3: Stayed with mother	1.57	.73
Item 4: Given daughter emotional support	2.32	1.14
Item 5: Helped with transportation	1.57	.81
Item 6: Heled with material goods	1.21	.61
Item 7: Checked on daughter	2.08	1.10
Item 8: Encouraged daughter	1.51	.73

Alpha Coefficient=0.76
Mean=1.79; Standard Deviation=0.55

Positive Beliefs about Caregiving

Positive beliefs about caregiving were calculated by using the mean score on the seven item self esteem scale from the Caregiver Reaction Assessment (Given et al., 1992). Responses to each item range from one to five on the following scale: 1) strongly disagree; 2) disagree; 3) neither agree or disagree; 4) agree; and 5) strongly agree. A higher score indicates more positive beliefs about caregiving. Item number seven "I wish my family depended on me less to care for my mother" was reverse scored in this scale. The alpha coefficient calculated on this sample was .80. The mean score for the positive beliefs about caregiving was 3.69 with a standard deviation of 0.64. Mean range on the scale was a minimum of 1.71 and a maximum of 5.00 (See Table 7 for Positive Beliefs).

Negative Beliefs about Caregiving

The negative beliefs about caregiving scale was calculated by using the mean score on the "sense of entrapment" sub scale (Stommel et al., 1990). Responses on the scale range from one (strongly disagree) to five (strongly agree) with a higher score indicating more negative beliefs about caregiving. The alpha coefficient calculated on this sample was .86. The mean score on the negative beliefs about caregiving was 2.77 with a standard deviation of 0.91. The mean ranges on the scale were a minimum of 1.00 and a maximum of 4.83 (See Table 8 for individual means on Negative Beliefs Scale).

Correlations were performed to test the two hypothesis proposed for this study which were: 1) Family support will be positively related to positive beliefs about caregiving; and 2) Family support will be negatively related to negative beliefs about caregiving. Correlations were performed between the variables of family support and positive beliefs and family support and negative beliefs using a .05 significance level. The hypothesis could not be supported by the correlations (See Table 9).

Table 7

<u>Item Means Positive Beliefs About Caregiving (n=118)</u>

	Mean	Standard Deviation
1. Caring for my mother is important to me	4.70	.50
2. I enjoy caring for my mother	3.76	.98
3. Caring for my mother makes me feel good	3.90	.82
4. I feel privileged to car for my mother	3.62	.98
5. I really want to care for my mother	4.09	.91
6. I will never be able to do enough caregiving to repay my mother	3.04	1.19
7. I wish my family depended on me less to care for my mother	2.73	1.15

Alpha Coefficient=.80
Mean=3.69; Standard Deviation=0.64

Table 8

Item Means Negative Beliefs About Caregiving (n=118)

	Mean	Standard Deviation
1. I feel overwhelmed by the problems I have caring for my mother	2.90	1.06
2. I get very discouraged caring for my mother	2.78	1.11
3. I feel I was forced into caring for my mother	2.77	1.34
4. I feel trapped by my caregiving role	2.71	1.23
5. At this time of my life, I don't think I should have to be caring for my mother	2.38	1.10
6. Just when I though times were going to be easier for me I have to be a caregiver	3.17	1.13
7. Since caring for my mother, sometimes I hate the way my life has turned out	2.61	1.29

Alpha Coefficient=.86
Mean=2.77; Standard Deviation=0.91

Table 9

Correlations Among Study Variables

	Negative Beliefs	Positive Beliefs
Family Support (n=118)	-.1371	.1551
	P=.139	P=.094

(Coefficient/(cases)/2-tailed Significance)

Discussion

The research question: **Among a group of caregiving daughters providing care to elderly mothers, is there a relationship between the perception of family support for the caregiving role and positive and negative beliefs about caregiving?** Could not be answered in this study. Despite the fact that the hypothesis in this study could not be supported, this researcher believes that some relevant data can be obtained from this study.

DISCUSSION AND IMPLICATIONS FOR RESEARCH AND PRACTICE

A discussion will follow that covers the sample, the variables of family support, positive feelings about caregiving and negative feelings about caregiving, as well as the statistical procedures used and the fit within the proposed model.

The sample used in this study is similar to other mother daughter samples used in mother daughter research (Horowitz, 1985; Walker & Pratt, 1991). At first glance, the sample seemed to be fairly burdened with tasks of ADL's (M=2.69, SD=2.21), IADL's (M=5.31, SD=1.13) and health care activities (M=3.09, SD=1.89) but on closer inspection, this may not be apparent. In viewing the data on ADL's, care recipients were fairly independent in areas such as eating, toileting and transferring. Areas requiring greater assistance included items such as bathing and dressing. While important, these are not high frequency items needing to be done several times per day.

In viewing IADL's, there was a high dependency in all areas except for money management which may represent an attempt on part of the elderly mothers to maintain some sense of control or independence. The IADL areas may be areas that the caregivers could ask for assistance from friends or families. Health care activities were not frequent with the exception of administration of oral medications which were required by the majority (92.5%) of the care recipients. Overall, this group of care recipients were fairly independent in areas of ADL's and HCA's which may impact upon the positive beliefs expressed by this group of caregiving daughters.

In viewing the social support scale, this researcher acknowledges that it appears to be a very global scale of family support and does not encompass many of the items present in social support. Social support is a multi-dimensional concept. An attempt was made to factor out the items in this scale and although it appears that more than one factor is present, it is not the case. Internal consistency was good for this scale with an alpha coefficient reported at 0.76.

In viewing family support in this study, participants overall scored relatively low on family support (M=1.79, SD=0.55). Viewing the individual scale items, participants scored highest on scale items "given you emotional support or encouragement" (M=2.31, SD=1.13), followed by "spent time keeping mother company" (M=2.18, SD=0.58), and "checked on you to be sure that you were all right" (M=2.08, SD=1.09). The lower score findings may be supported by the Brody (1989) study in which caregivers exceeded groups of siblings in the ways siblings were meeting parental care responsibilities. "Two thirds of the caregivers in this study felt that a sibling had not visited the mother enough, had wanted to be asked before helping or could have helped more; more than one half felt that a sibling had not called or had not done a fair share of parent care" (Brody, 1989, p. 532). These feelings of low family support may also be related to the new caregiver role with the daughters concentrating on mastering the role and the inability to seek assistance for a variety of reasons. Another possible explanation for the low scores on the scale may be the fact that the scale does not capture the concept of family support.

Positive beliefs were evident in this study on the positive belief scale (M=3.69, SD=0.64) with 3=neither agree or disagree and 4=agree. Beliefs that were viewed as most positive included, "caring is important to me (M=4.70, SD=0.50) and "really want to provide care" (M=4.09, SD=0.91). Interestingly, the lowest item on the positive scale was "never able to repay" (M=3.04, SD=1.19). These positive responses may express the daughter's willingness, commitment and desire to care for their mothers.

Negative beliefs were not strongly expressed in this study on the negative beliefs scale (M=2.77, SD=0.91) which corresponded to 2=disagree and 3=neither agree or disagree. Items on the scale that scored the highest mean score included, "Just when I thought things were going to get easier for me, I had to be a caregiver" (M=3.17, SD=1.31) and "I feel overwhelmed by the problems I have caring for my mother" (M=2.90, SD=1.06). The higher means on these items may be capturing the realization of the newness of taking on the caregiver role as well as a feeling of being overwhelmed with responsibilities demanded by the role. Perhaps an explanation may be the newness of the caregiving role and exploration of the role as the data gathered in this study occurred shortly after the start of the caregiving experience.

The majority of literature on the caregiving experience does not address the issues of caregivers new to the role. Caregivers included in the studies have a variable length of caregiving experience. The negative aspect of caregiving is much more prevalent in the literature than the positive aspects of caregiving.

Conceptual Model

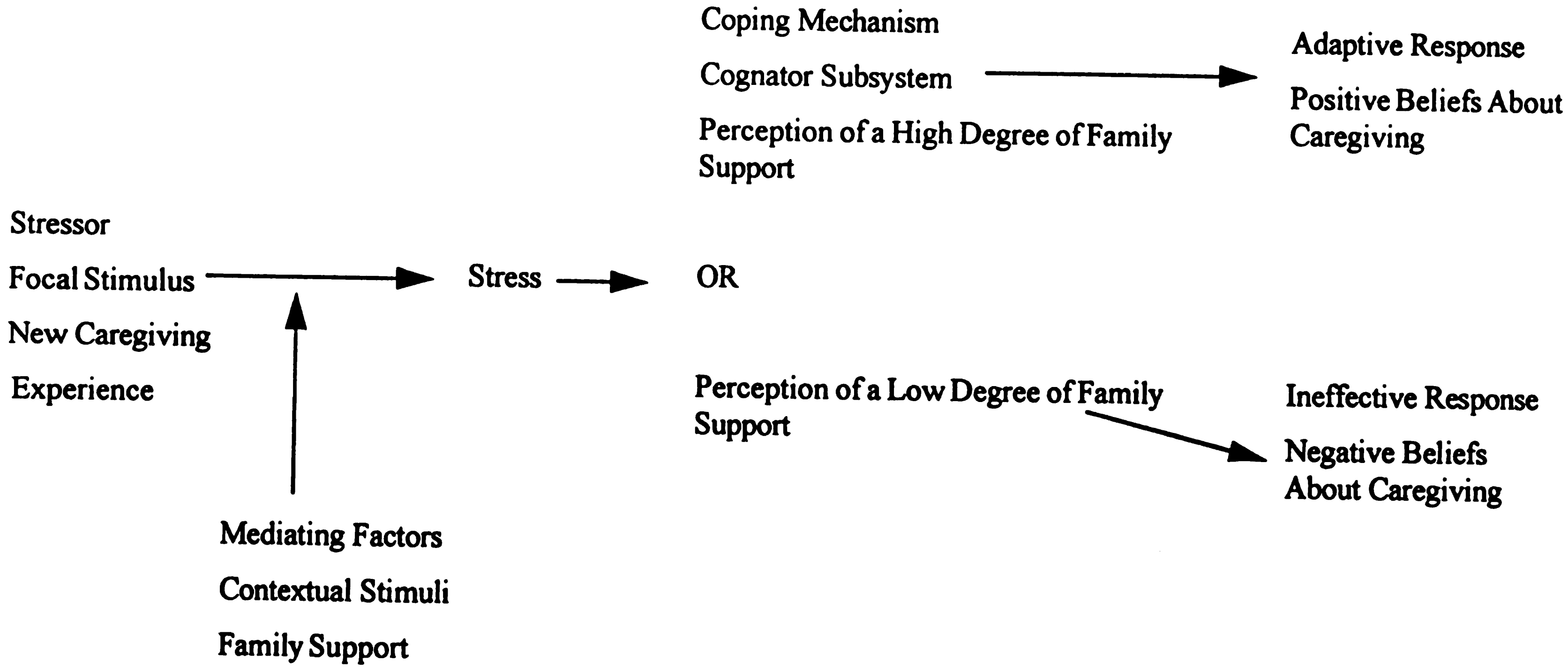
Although the hypothesis could not be supported in this study, this researcher believes that more research needs to be done before the model is rejected. Although it is early, an improvement suggested on the model may be the clarification of the model by further identifying family support as a high degree of family support or as a low degree of family support. As the model is conceptualized presently, degree of family support is not specified and groups all types of family support may diminish the impact of family support either high or low on the positive or negative beliefs about caregiving. See Figure 4 for revised model.

The division of the sample into groups of high family support and low family support may strengthen correlations between the variables as well as allow for comparison between groups using statistical procedures such as ANOVA. In future research using this scale, it might be useful to define high family support by including individuals who scored two or over in one group and those who scored less than two in a low family support group. A disadvantage of this approach may be a disproportionate amount of individuals in one group or the other. Another suggestion may be to form groups using the mean and one half of the standard deviation for each group. The disadvantage to this approach will be the loss of a part of the sample group.

Limitations

As previously mentioned, the Social Assistance Scale (Barnes & King, 1990) has not been tested previously and no psychometric data is available. Initial psychometrics obtained in the present study were promising with an initial Alpha Coefficient of 0.76. Further testing of the scale among additional groups is definitely indicated.

Figure 4. The Stress Adaptation Process as Related to Caregiving and Family Support - Revised Model



Implications for Nursing Practice

There are many implications for the CNS in primary care. Throughout the literature, there seems to be an abundance of information about the negative aspects of caregiving. This negative theme seems to carry through into primary care with the primary care providers focused on the negative aspects of caregiving. Many times the primary care provider is not aware of the caregiving situation until negative consequences are apparent. Women as caregivers may be stressed by work and family obligations as well as the caregiving situation itself. Bunting (1989) reports, "Negative consequences of caregiving for the caregivers themselves include the emotional stresses of coming to terms with the changing role and capability of the older person; the restrictions on time and freedom; the economic burdens, including loss or curtailment of employment; and the detrimental effects on the caregiver's marital, family and social relationships" (p. 65). The CNS should be alert to symptoms such as fatigue, inability to sleep, depression, complaints of decreased socialization or feeling of abandonment that may accompany the caregiver role.

The Advanced Practice Nurse must realize that many women the CNS may see in practice may be experiencing the caregiving role by caring for elderly parents. The CNS should incorporate questions into the practice that will point out individuals who may be in a caregiving situation. This current study of new caregivers seemed to project that many positive feelings are associated with the caregiving experience. It is also important that the CNS be aware of and acknowledge the positive aspects and beliefs of caregiving and support the positive beliefs that the daughter may hold and help the daughter maintain a perspective on the caregiving situation. It is important that interventions for caregiving start early in the course of caregiving which may be a step in minimizing some of the negative aspects associated with the role. The CNS must also realize that caregiving is often long term ongoing commitment which should be assessed at intervals as part of the care of the caregiving daughter.

The study presented here utilizes a sample of caregivers relatively new to the caregiving role who are taking care of individuals recently released from the hospital. Education of caregivers is an essential nursing intervention by the CNS in working with caregivers. The CNS may also utilize information in this study when working with new caregivers to give ideas about types of responsibilities they might anticipate. Recipients in this study needed assistance with many of the ADL's such as dressing, bathing, walking in the house, transferring, toileting, and eating. Health care activities such as administering oral medications, exercises, treating skin problems, urine and stool incontinence, and oxygen administered were prevalent in this group. The CNS can be instrumental in educating the caregivers about these types of activities.

Most commonly daughters in this study indicated needing a high percentage of assistance with IADL's such as transportation, shopping, housework, laundry, cooking, and money management. The CNS can help the caregivers to think about alternative strategies for accomplishing some of these tasks associated with caregiving.

The daughters in this group indicated the perception of very little family assistance. The CNS could explore family assistance availability with the women and encourage a more collaborative effort with other family members if feasible or explore other resource options that the caregiving daughters may use such as respite care, day care or other community services. The caregiving daughters may need to be "given permission" to use family or other options for assistance. It is essential that the CNS be aware of resources in the community that may be available and the obstacles or barriers that the caregiver may experience trying to assess the services so the caregiving daughter will not be discouraged accessing services. Daughters may be reluctant to access help from other family members or community services so anticipatory guidance may be a good strategy to use so that the daughters can access services when appropriate. The CNS can stress the importance of getting emotional support from family members to the caregiving daughter during the caregiving situation. The importance of giving emotional support to the caregiving daughter should be stressed to various family members as available.

By utilization of supports and community assistance, the caregiving daughters may be able to maintain employment. Employment issues should be discussed and attempts made to work out a possible solutions with the caregiving daughter as loss of employment could have long term effects on the daughter's future.

This sample was relatively new to the caregiving role and positive feelings were apparent. It is interesting to note that although caregivers in this study rated care recipient's physical health as fair to poor, mental health was rated as good to fair by caregivers. The CNS should be aware that changes in status may increase the negative response to the caregiving situation. It is important that the CNS acknowledge the positive aspects of caregiving as well as the negative aspects that may accompany the role. This may help to normalize ambivalent feelings for the caregiver. The CNS can work with the women on an individual basis to work out specific strategies that may help the daughter to cope with the caregiving role.

Another role for the CNS is to encourage education of the public in regards to the caregiving role. The role of caregiver should be discussed in nursing education, women's health classes, and perhaps even community education classes.

Implications for Further Research

In general, research on caregiving needs to continue as individual life expectancy continues to expand and family size decreases. Researchers need to continue to look for answers to questions, "What is the role of family support in caregiving?" and "What influence does family support have on positive and negative feelings about caregiving?" Strategies will need to be developed to keep the elderly in the community. It is important to continue to look at groups such as spouses, siblings, daughters, and sons differently as each group have some unique characteristics and beliefs about the caregiving role.

The Social Assistance Scale (Barnes & King, 1990) needs more testing and revision as this project is the first documented use of the scale. The scale needs to be modified to encompass more aspects of family support as well as used among a variety of different caregivers to see if differences exist in the perception of family support by the caregivers. Longitudinal studies may be also indicated to study how the perception of family social assistance varies over time.

For this particular project, a longitudinal study may be interesting to see if family social assistance becomes more apparent as the length of the caregiving experience expands. It may also be beneficial to use additional tools that could supplement the family social assistance scale. According to Kane (1988), family support is a multidimensional concept so adding additional scales that capture the realms of reciprocity, advice/feedback, and emotional support may increase the opportunity to fully understand the role that family support plays in the caregiving experience.

For future use in research it may be beneficial to examine the positive belief scale (Given et al., 1992) and consider altering the reverse scored question. This question seems to have a lower mean both in this study as well as the Pohl (1992) study and may be influencing the overall mean of the scale. Options that might improve response on this question might include changing the order of the question in the scale so that the reverse nature is more apparent or else consider changing the wording to require a response similar to other questions in the scale.

This study addressed caregivers relatively new to the role. Further research should be done to study the new caregivers as the individuals adjust to the role. Research also needs to be done comparing relatively new caregivers to seasoned caregivers to determine similarities and differences among groups. An additional opportunity for research would be to longitudinally study how positive and negative feelings vary as the length of the caregiving experience increases.

Since the focus of this study is mother daughter caregiving, this researcher acknowledges the fact that biases may be present in the findings. With the recent changes in the lives of women, such as increased full time employment, and the blurring of gender lines with men now taking on some of the roles traditionally associated with women, more research needs to be done on the roles that men play in the role of caregiving.

In conclusion, although no correlation could be demonstrated between family social assistance and positive and negative feelings about caregiving, several important factors were implied by the project. The new caregivers in this group implied that as a group, it was felt that very little assistance was available to them from family members. It is also important to recognize the positive feelings that were expressed by this group and how important the caregiving experience was to them. In this particular study of relatively new caregivers, positive feelings were more strongly expressed than negative feelings. These factors could have great implications for the CNS in a primary care role.

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APPENDICES

APPENDIX A

ID	_ _ _	1-3
CARD	0 1 8	4-6
DATE	_ _/_ _/_ _	7-12
INT	_ _	13-14
INTCODE	1	15
STUDY	5	16

CAREGIVING INVENTORY

We are trying to understand how providing care for your family member has affected you, your relationships with others, and your social activities and daily routines.

In the questions that follow, please circle the response that most represents <u>how you feel</u> about each statement. <u>**The blank line in some statements represents the name of the elderly person for whom you provide care**</u>. It may be helpful (but is not necessary) for you to place the initials of the person on the blank line. Answer all the questions in response to caring for your relative. Please circle one number for <u>each</u> statement using the code below:

5 = STRONGLY AGREE
4 = AGREE
3 = NEITHER AGREE OR DISAGREE
2 = DISAGREE
1 = STRONGLY DISAGREE

(CIRCLE ONE NUMBER FOR EACH)

1.	My activities are centered around care for _____.	**5 4 3 2 1**	__ 17
2.	I am healthy enough to care for _____.	**5 4 3 2 1**	__ 18
3.	My family works together at caring for _____.	**5 4 3 2 1**	__ 19
4.	Caring for _____ is important to me.	**5 4 3 2 1**	__ 20
5.	Since caring for _____ I have enough time for myself.	**5 4 3 2 1**	__ 21

5 = STRONGLY AGREE
4 = AGREE
3 = NEITHER AGREE OR DISAGREE
2 = DISAGREE
1 = STRONGLY DISAGREE

(CIRCLE ONE NUMBER FOR EACH)

6.	I feel overwhelmed by the problems I have caring for _____.	**5 4 3 2 1**	__ 22
7.	It takes all my physical strength to care for _____.	**5 4 3 2 1**	__ 23
8.	I enjoy caring for _____.	**5 4 3 2 1**	__ 24
9.	I wish the family depended less on me to care for _____.	**5 4 3 2 1**	__ 25
10.	I have to stop in the middle of my work or activities to provide care.	**5 4 3 2 1**	__ 26

ID _ _
CARD 0 1 8

5 = STRONGLY AGREE
4 = AGREE
3 = NEITHER AGREE OR DISAGREE
2 = DISAGREE
1 = STRONGLY DISAGREE

(CIRCLE ONE NUMBER FOR EACH)

11.	My health has gotten worse since I've been caring for _____.	5	4	3	2	1	27
12.	Since caring for _____, I feel my family has abandoned me.	5	4	3	2	1	28
13.	Caring for _____ makes me feel good.	5	4	3	2	1	29
14.	I have enough time for leisure and recreational activities since caring for _____.	5	4	3	2	1	30
15.	It is very difficult to get help from my family in taking care of _____.	5	4	3	2	1	31
16.	Being a caregiver prevents me from taking care of my own health.	5	4	3	2	1	32
17.	I feel privileged to care for _____.	5	4	3	2	1	33

5 = STRONGLY AGREE
4 = AGREE
3 = NEITHER AGREE OR DISAGREE
2 = DISAGREE
1 = STRONGLY DISAGREE

(CIRCLE ONE NUMBER FOR EACH)

33

18.	Other have dumped caring for _____ onto me.	5	4	3	2	1	34
19.	I have eliminated things from my schedule since caring for _____.	5	4	3	2	1	35
20.	I believe it is my responsibility to care for _____.	5	4	3	2	1	36
21.	I get very discouraged caring for _____.	5	4	3	2	1	37
22.	I have enough physical strength to care for _____.	5	4	3	2	1	38
23.	The constant interruptions make it difficult to find time for relaxation.	5	4	3	2	1	39
24.	My family (brothers, sisters, children) left me alone to care for _____.	5	4	3	2	1	40

ID ___ ___
CARD 0 1 8

5 = STRONGLY AGREE
4 = AGREE
3 = NEITHER AGREE OR DISAGREE
2 = DISAGREE
1 = STRONGLY DISAGREE

(CIRCLE ONE NUMBER FOR EACH)

25. Since caring for _____, it seems like I'm tired all of the time. 5 4 3 2 1 ___ 41

26. I really want to care for _____. 5 4 3 2 1 ___ 42

27. Since caring for _____, sometimes I hate the way my life has turned out. 5 4 3 2 1 ___ 43

28. I visit family and friends less since I have been caring for _____. 5 4 3 2 1 ___ 44

29. Taking care of _____ has <u>not</u> affected my physical health. 5 4 3 2 1 ___ 45

30. I feel I was forced into caring for _____. 5 4 3 2 1 ___ 46

31. I have enough time to do my own work and chores since caring for _____. 5 4 3 2 1 ___ 47

5 = STRONGLY AGREE
4 = AGREE
3 = NEITHER AGREE OR DISAGREE
2 = DISAGREE
1 = STRONGLY DISAGREE

(CIRCLE ONE NUMBER FOR EACH)

32. I will never be able to do enough caregiving to repay _____. 5 4 3 2 1 ___ 48

33. I feel trapped by my caregiving role. 5 4 3 2 1 ___ 49

34. Since I began taking care of my relative, I take better care of <u>my</u> health. 5 4 3 2 1 ___ 50

35. I sleep just as much since caring for _____. 5 4 3 2 1 ___ 51

36. At this time in my life, I don't think I should have to be caring for _____. 5 4 3 2 1 ___ 52

37. I am sick more often since I began caring for my relative. 5 4 3 2 1 ___ 53

38. I could not live with myself if I just quit caring for _____. 5 4 3 2 1 ___ 54

39. Just when I thought times were going to be easier for me, I have to be a caregiver. 5 4 3 2 1 ___ 55

ID ___
CARD 0 1 8

Please remember we are trying to understand how providing care for your family member has affected you. Please circle one number for each statement using the code below:

4 = A GREAT DEAL
3 = QUITE A BIT
2 = SOME WHAT
1 = VERY LITTLE

(CIRCLE ONE NUMBER FOR EACH)

To what extent ...

40.	do you get frustrated with your situation?	4 3 2 1	___ 56
41.	are you so frustrated that you have to leave the room?	4 3 2 1	___ 57
42.	did you get angry with the person for whom you were providing care?	4 3 2 1	___ 58
43.	do you feel that you are manipulated by the person for whom you were providing care?	4 3 2 1	___ 59

4 = A GREAT DEAL
3 = QUITE A BIT
2 = SOME WHAT
1 = VERY LITTLE

(CIRCLE ONE NUMBER FOR EACH)

44.	did you resent the fact that others didn't help provide care?	4 3 2 1	___ 60
45.	do you believe your relationship with your relative is strained?	4 3 2 1	___ 61
46.	did you become irritated with the person for whom you provided care?	4 3 2 1	___ 62
47.	did you resent the way your life has turned out?	4 3 2 1	___ 63
48.	did you get so angry you have to stop what you are doing?	4 3 2 1	___ 64
49.	do you get so upset that it interferes with caring?	4 3 2 1	___ 65

SOCIAL ASSISTANCE

The questions I just asked were about the assistance that you receive through agencies. Now I'm going to ask you questions about the assistance that you may receive from other people to care for your (relationship or name of patient). By other people, I mean friends or relatives whether you pay them or not.

For the next set of questions, I will ask "How often since discharge, over the past month, has anyone in your family given you assistance in the following ways," and I will read a list of activities. I would like you to please pick from one of four categories of responses: You can choose from "Rarely or None of the Time," "Some of the Time," "Most of the Time," or "Almost all of the Time." I will repeat those categories again if necessary.

1. How often since discharge or over the past month, HAS ANYONE IN YOUR FAMILY given you assistance in the following ways: (CHECK ONE FOR EACH TASK)

	(1) RARELY OR NONE OF THE TIME	(2) SOME OF THE TIME	(3) MOST OF THE TIME	(4) ALMOST ALL OF THE TIME
A) Help with physical care.				
B) Spend time keeping your (Care Recipient) company.				
C) Stayed with ____ so that you could do something else for a few hours.				
D) Given YOU emotional support or encouragement.				
E) Helped with transportation - for either you or (Care Recipient).				
F) Helped YOU with money or other material goods.				
G) Checked on YOU to be sure that you were all right.				
H) Provided or encouraged diversional activities for (care recipient), such as cards or scrabble, etc.				

APPENDIX B

MICHIGAN STATE
UNIVERSITY

June 9, 1995

TO: Carol Wank
204 Park Meadows
Lansing, MI 48917

RE: IRB#: 95-305
TITLE: THE PERCEPTION OF FAMILY SUPPORT RELATED TO POSITIVE AND NEGATIVE BELIEFS ABOUT CAREGIVING AMONG A GROUP OF DAUGHTERS CARING FOR ELDERLY MOTHERS
REVISION REQUESTED: N/A
CATEGORY: 2-H
APPROVAL DATE: 06/08/95

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, Ph.D.
UCRIHS Chair

DEW:kaa/lcp

cc: Barbara A. Given

OFFICE OF
**RESEARCH
AND
GRADUATE
STUDIES**

**University Committee on
Research Involving
Human Subjects
(UCRIHS)**

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