FAMILY CAREGIVING: FAMILY STRAINS, COPING RESPONSE PATTERNS, AND CAREGIVER BURDEN

by

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(ABSTRACT)

This study addressed gaps in the literature on caregiver burden involving lack of information about the multiple strains of caregiving families, their coping patterns, and postive as well as negative aspects of caregiving. The primary objective was to examine the relationship among caregiving strains, patterns of coping responses employed, and the resulting objective and subjective burden. A model describing the relationship of these variables guided the study. The design was a mail survey of 97 caregivers living in Southwestern Virginia who were caring for a sick or disabled family member, age 60 or older (response rate=81%).

Family strain was correlated with both subjective and objective burden. Only one coping pattern that dealt with understanding the medical situation was marginally correlated with objective burden at $p < .10$. No coping patterns were correlated with subjective burden. Based on stepwise multiple regression analysis, the variables that were significant in explaining the variance in objective burden were health of the caregiver and family strain. The presence of home health services and family strain were significant in explaining the variance in subjective burden. Qualitative analysis identified major themes of positive and negative aspects of caregiving, with the majority of caregivers reporting both.

Implications of these findings for future research include the importance of examining family strain when studying caregiver burden, assessing problems with the conceptualization of coping, evaluating the effectiveness of different measures of coping patterns, and investigating the balance of costs and rewards related to caregiving. Implications for practice include the importance of health workers considering multiple sources of strain in the family. Caregivers need optimistic but realistic information about the situation. Staff members should promote the caregiver's confidence in the management of the medical situation. Governmental and service agencies need to assist caregivers in relieving problems with restrictions on time and activities, and provide an opportunity for the exchange of information about managing home care. Future researchers need to study the influence of home health services on caregiving by comparing the coping patterns and subjective and objective burden of caregivers who receive this service and those who do not.

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Chapter I: Introduction

Whereas most people over sixty years of age are healthy and able to live independently, only about 14% of non-institutionalized elderly persons are free of chronic disease (Yurick, Robb, Spier, Elber, & Magnussen, 1980). Estimates of the proportion of non-institutionalized elderly who are in need of help vary from 17% to 40% (Brody, 1985). Beyond age 85, the percentage needing help goes to 71.8% (Yurick et al., 1980).

Who provides the care the non-institutionalized elderly person needs? Researchers have shown that families provide most of the care and link the older person to the formal support system (Shanas, 1979). The main source of help is the spouse (Cantor, 1983). These wives and husbands, usually elderly themselves, often need outside help. Children, either within or outside the household, are the ones most likely to help (Shanas, 1979). Although the percentage of women who are employed steadily increases, daughters continue to be the main source of assistance to elderly parents (Brody, 1981; Cantor, 1983).

Brody (1985) estimated that, at any given time, over 5 million people are involved in caring for elderly family members and this does not include all those who have provided care to an elderly family member in the past or who will do so in the future. When the family is called upon to care for a dependent member, adjustments must usually be made in family roles and tasks. The potential for stress exists. Many investigators have identified the stresses, hardships, and burdens that result (e.g., Horowitz & Dobrof, 1982; Robinson & Thurnher, 1979) and a few have studied how primary caregivers cope with problems associated with caregiving. It appears, however, that no known researchers have looked at the multiple strains in primary caregivers' lives and how they cope with them.

Specific Aims

The primary aim of the present research was to identify the coping response patterns used by family caregivers in dealing with the strains of caring for a dependent elderly family member. Although studies have shown that caregiving is stressful for most caregivers, especially those caring for persons with Alzheimer's and other dementing illnesses, few have identified the coping strategies used by caregivers or evaluated their efficacy. Moreover, most researchers have focused on only one primary caregiver rather than the caregiving family. The hypothesis was that the primary caregiver's level of burden will vary depending on the other strains present in the family and the particular coping response patterns used. Because many intervention programs are based on the assumption that caregivers for the elderly have similar strains and methods of coping, the results provide information that policy makers and clinicians can use in making decisions concerning appropriate interventions.

Research Variables

The Context of Caregiving

In each family the context of caregiving varies depending on the unique characteristics of individual family members, the strains in multiple areas of the members' lives, and the resources for dealing with these strains. Although it is impossible to identify all the factors that impact on the life of a family, I studied the following variables in an attempt to understand the caregiving situation.

Carereceiver. The definition of carereceiver is an impaired elderly person who is requiring assistance from family members. The physical and mental conditions that can produce this need for assistance vary greatly. The disabilities resulting from a diagnosed condition can also vary greatly. Many elderly persons experience more than one disease condition simultaneously. Therefore, in order to understand the caregiving context, it is important to examine the functional limitations that the carereceiver experiences as a result of the disease processes, and the tasks with which the family must assist.

Primary caregiver. The definition of primary caregiver is a lay person, usually a family member, who is responsible for providing daily assistance. The primary caregiver may also assist with or provide decision making for the impaired elderly member. Lubkin (1986) stated that caregiving falls into two categories: care providers and care managers. Care providers perform needed services themselves and expend most of their time and energy on performing physical and personal care. Care managers, on the other hand, arrange for others to provide services and use their time and energy learning about available resources and arranging for appropriate services. Care managers often have more time and energy to focus on psychosocial needs than do care providers. The roles of care provider and care manager may be split between members in a family or one member may perform both roles. This study focused on the family member most directly involved in the day-to-day care of the impaired elderly member. If the roles of care provider and care manager were split between family members, I asked the care provider to respond to the questionnaire because I assumed that this family member experiences the greatest degree of burden due to the daily expenditure of time and physical and emotional energy.

Relationship between caregiver and carereceiver. The primary caregiver is usually a spouse if she or he is able. Most frequently, it is the wife providing care for a disabled husband. According to Hooyman and Lustbader (1986), an implicit but unspoken assumption of family members and service personnel is that when a wife is present, she can and should care for her husband. However, when the spouse is unable to be the caregiver or the disabled person no longer has a spouse, the responsibility for providing care normally falls to the carereceiver's closest relative, usually a child or children if available.

Whereas most children, particularly daughters, provide help when it is needed, help giving is not usually shared equally among siblings. Matthews (1987) studied how children divided the responsibility for caring for older parents (age 75+) and found that structural characteristics of families affected the way they divided responsibilities. Equal sharing occurred most often when there were only two adult children. When there were four or more siblings, a much higher proportion of families reported that not all children helped. With respect to gender, families that included brothers were more likely to be described as "mixed" with not all helping.

Employment status of the caregiver. The ability to provide assistance to impaired family members is influenced by other responsibilities in the caregiver's life. Brody and Schoonover (1986) compared the patterns of help to 150 disabled elderly widows for daughters who were employed and those not employed. Daughters from both groups provided equal amounts of help with such tasks as shopping and providing transportation, managing money and service arrangments, assisting with household tasks, and providing emotional support. Employed daughters provided less assistance with personal care and cooking, however. These services were usually purchased by the older person or family rather than provided by government subsidies or community agencies. This study inquired about the primary caregiver's employment status and assistance with tasks.

Marital status of the caregiver. Cicirelli (1983) compared the help that adult children with intact marriages and disrupted marriages provided for elderly parents and found that marital disruption affects the level and types of help given. The amount of help given by children who were divorced, widowed, or remarried showed no difference. Children with disrupted marriages, however, gave less total help and less help with seven of 16 specific services than children with intact marriages. In addition, children with disrupted marriages perceived lower parental needs, felt less filial obligation, and reported more limits in the ability to help primarily due to job responsibilities. Although the present study did not address the satisfaction or supportiveness of the marital relationship for the primary caregiver, it did provide information about whether the caregiver was in an intact marriage or unmarried.

Health of the caregiver. The health of the caregiver may also influence the ability to provide care. Goladetz, Evans, Heinritz, and Gibson (1969) found that more than one-half of the caregivers in their study had significant illnesses of their own. Fengler and Goodrich

(1979) described the caregivers in their study as "the hidden patients" because all mentioned at least one chronic illness and their life satisfaction and morale scores were similar to their husbands'. The present study inquired about the primary caregiver's perception of her or his own health status.

Age of the caregiver. The percentage of the population living to an advanced age (75+) has increased steadily since 1900 and demographers predict that it will increase to around 40% of the elderly population by the year 2000. Cicirelli (1981) predicted that many children of the advanced elderly will themselves be reaching the young-old stage (60-75) and experiencing declines in energy, finances, and health when their parents require assistance. Therefore, the age of the primary caregiver was an important variable to examine in order to see if, in fact, this transition is already occurring.

Resources for caregiving. The resources for providing care to an impaired elderly member include the informal support from family members, the financial resources available, and the formal support services available within the community. In this study, I obtained information about the primary caregiver's evaluation of the degree of assistance provided by family members and other sources of informal support. In addition, I requested information about the family's financial resources, and the formal services utilized by the family.

Main Research Variables

Besides the variables dealing with the context of the caregiving situation, the main variables of interest in the study included: the caregiving family's strain, coping response patterns, and the primary caregiver's objective and subjective burden. Figure 1 gives a conceptual illustration of the hypothesized relationships among research variables.

Family strain. Problems and life changes that have the potential for arousing threat constitute family strain. They impact upon the primary caregiver and caregiving family's way of functioning to produce an actual or perceived need for adaptive behavior. The sources of strain can be from multiple areas of life such as work, marital and intrafamily relations, finances, and business (McCubbin, Patterson, & Wilson, 1981).

Coping Response Patterns. Coping responses are those adaptive behaviors that caregivers and their family members use to deal with the strains they encounter. Pearlin and Schooler (1978) suggested that persons cope more effectively when they use a variety of coping mechanisms. Over time, a pattern of responding to encountered strain usually develops with similar coping responses being used to cope with similar strains. The definition for coping response patterns was similar to Menaghan's (1982) definition of coping style. Coping patterns are those habitual preferences for ways of approaching problems. McCubbin, Olson, and Larsen (1981) grouped family coping patterns into two dimensions--internal and external coping patterns. Internal coping patterns refers to ways in which family members handle problems between members, such as problem solving, reframing problems, or using passivity or inactivity to cope with difficulties. External coping patterns refers to ways in which the family handles problems that emerge externally from the social environment and includes the family's tendency to use church/religious resources, to seek help and

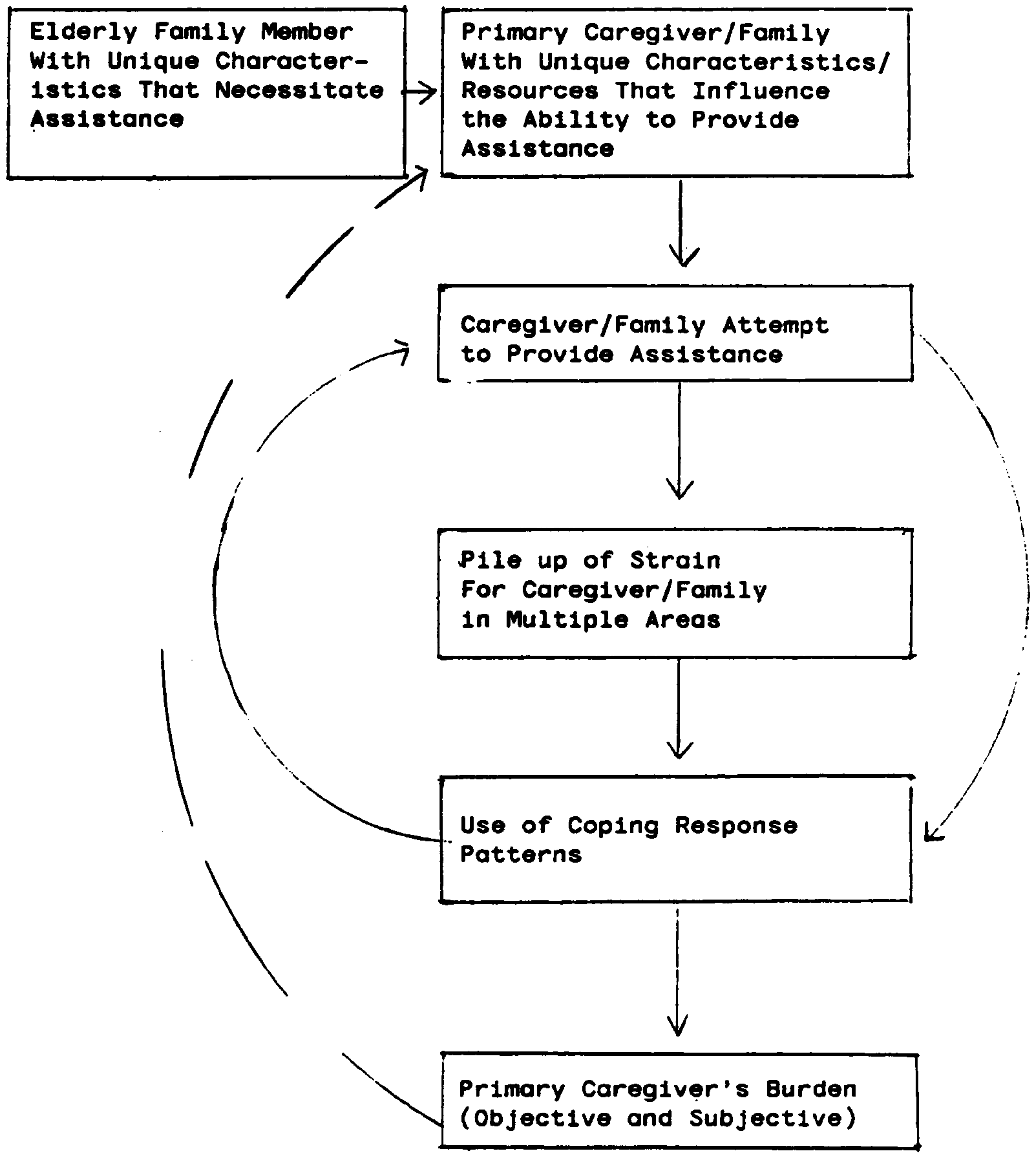

FIGURE 1: Conceptual Model of Research Variables

support from extended family members and neighbors, and to utilize community resources.

Caregiver Burden. Previous investigators have found the impact of caregiving to include changes in family relationships (Deimling & Bass, 1986: Robinson & Thurnher, 1979); disruptions in daily life or infringements on established routines (Robinson & Thurnher, 1979); and physical and emotional strain for the caregiver (Snyder & Keefe, 1985). Caregiver burden is the cost to the caregiver as the result of attempting to provide care for the impaired member. In some reports, authors use the term caregiver strain instead of burden. Researchers have identified the correlates of caregiver strain or burden to include the relationship of the caregiver to the carereceiver (Cantor, 1983), social supports (Zarit et al., 1980), type of assistance needed (Hooyman, Gonyea, & Montgomery, 1985), and the caregiver's health status (Pratt, Schmall, Wright, & Cleland, 1985). In this study, I used the definitions for caregiver burden proposed by Montgomery, Gonyea, & Hooyman (1985, p. 21). Objective burden is the extent of disruptions or changes in various aspects of the caregiver's life and household. The operational definition of objective burden was the amount of change that the caregiver had experienced in nine areas of her or his life since beginning to provide care for the carereceiver. These nine areas included the amount of time for self, privacy, money, personal freedom, energy, time for social or recreational activities and vacations, and changes in the caregiver's health and relationship with other family members.

Subjective burden reflects the caregiver's attitudes toward or emotional reactions to the caregiving experience. The operational definition of subjective burden was how often the caregiver experienced negative and positive feelings related to caregiving and the carereceiver while providing care. The negative or unpleasant feelings included feeling pain at watching the relative age, fear about what the future holds, strain in the relationship with the carereceiver, nervous and depressed about the relationship with the carereceiver, and guilt about the relationship and not doing as much for the carereceiver as could or should be done. Four emotional reactions related to how the caregiver was treated by the carereceiver and included feeling that the carereceiver tries to manipulate or control, makes requests that are over and above what she or he needs, does not appreciate what is done for her or him, and seems to expect the caregiver to take care of her or him as if she or he was the only one that can be depended on. The positive emotional responses dealt with feeling useful in the relationship with the carereceiver, that the caregiver is contributing to the well-being of the relative, and pleased with the relationship with the carereceiver. The study quantitatively and qualitatively explored caregivers' perceptions of the positive and negative aspects of providing care.

Objectives of the Study

The aim of the research was to identify whether there is a relationship among the strains experienced, the patterns of coping responses employed, and the resulting subjective and objective burden of the primary caregiver. The hypothesis was that, if the primary caregiver is using patterns of coping responses that are conducive to positive well-being and health, the caregiver's subjective and objective burden scores will be low. As I demonstrated in Figure 1, the variables are related in a cyclic fashion. The level of subjective and objective burden will influence the unique characteristics of the primary caregiver and his or her family that will influence further attempts to provide assistance. This continued or new assistance may produce strain in multiple areas of the family's life that will necessitate the further use of coping strategies. All these influence the primary caregiver's subsequent perception of burden.

Four objectives influenced the organization of the data analyses. First, I used selected demographic data to identify whether there were unique characteristics of the primary caregiver and the carereceiver that contributed to the objective and subjective burden perceived by the caregiver. The second objective was to identify the pile up of strains in multiple areas of the caregiving family that have the potential for impacting on the primary caregiver's ability to provide care for the elderly member and the level of caregiver burden. The third objective was to identify the coping response patterns that caregivers have used to manage their problems and crises and to determine the levels of subjective and objective burden associated with various coping patterns. The fourth objective was to examine the relationship between subjective and objective burden and the family strains, the coping response patterns, and significantly correlated contextual variables.

Contributions of the Study

This study contributes to the existing research on caregiving in two ways. First, the focus of the study was on the caregiving situation within the context of the family rather than focusing on only one primary caregiver (which has occurred in most previous studies). Although Thompson and Doll (1982) spoke of the need to study the "silent stress pile-up" related to caregiving, apparently no other studies have focused on the multiple areas of potential strain within the caregiving family.

Secondly, I viewed caregiving as a constant, everyday potential source of strain that contains both positive and negative effects for family members. Although a few studies (e.g., Chenoweth & Spencer, 1986; Fitting, Rabins, Lucas, & Eastham, 1986) reported that caregiving had improved the caregiver/carereceiver relationship or had drawn family members closer together for at least some of their sample of caregivers, most studies have focused on the negative effects of caregiving on family relationships (e.g., Deimling & Bass, 1984; Johnson & Catalano, 1983) and neglected the positive effects. In this study, I explored the positive as well as negative effects that caregivers experienced from caregiving.

In summary, the significance of the present study is that it provides information about the patterns of coping responses used by caregivers in situations where they are helping provide care for a frail elderly member in a home setting. This information will be helpful to policy makers in planning intervention programs and to clinicians in counseling caregivers and their families. If caregivers can cope more effectively with the strains that caring for a dependent family member brings and derive satisfaction from caregiving, more elderly members will be able to remain in the community for longer periods.

Chapter II: Review of the Literature

Investigators have conducted many studies of the experience of caregiving for dependent elderly persons. Much of this research has centered around the experience of caregiving for persons who are demented and particularly those with Alzheimer's disease. Because I was interested in examining how family caregivers cope with caring for impaired elderly members with a variety of health problems and impairments, I did not limit the literature review to studies of caregivers for patients with any particular diagnosis. Rather, I focused it on the impact of caregiving on caregivers for elderly family members, correlates of caregiver burden across caregiving situations, and issues in the measurment of caregiver burden.

Impact of Caregiving

Kingston, Hirshorn, and Cornman (1986) described the normal everyday reciprocal exchange of family caregiving and carereceiving that occurs over the life course as ordinary family caregiving. These ordinary exchanges include maintenance support, such as help with daily chores, financial assistance, and gift giving; and emotional support, such as advice on major decisions or purchases, and expressions of affection and approval. Over the life course, there is usually a two-way direction in the exchange of care. The family must give extraordinary care, however, when chronic or serious illness or injury occurs that necessitates a more demanding form of assistance and support than that required by most everyday needs. In this situation the carereceiver is primarily on the receiving end and may have few resources for active reciprocity. When this occurs, family life is quickly and radically altered, perhaps for an extended period of time.

Impact on Daily Life

Most studies have focused on the ways in which caregiving has changed the caregiver's life and the stress or strain experienced as result of these changes. Robinson and Thurnher (1979) studied the experiences of 49 adult children as they cared for aged parents over a six and one-half year period. They found that stress resulted when the family members experienced the caretaking relationship as confining. This confinement was linked less clearly to the physical or mental status of the parent than to infringements on the caregiver's lifestyle. Chenoweth and Spencer (1986), in their study of 79 home caregivers of family members with Alzheimer's disease, found that the third most often reported problem with providing care at home was the caregiver's inability to get away from home.

Changes in the Relationship Between the Caregiver and Carereceiver

Most researchers report changes in the relationship between the caregiver and carereceiver as a result of caregiving. The changes are usually identified to be negative or conflictual. Johnson and Catalano (1983), in a longitudinal study of 167 families providing support to an older person discharged from the hospital, found that when poor health and dependence persisted, the patient's mood and satisfaction with social supports declined and more conflict occurred between the patient and the caregiver.

Poulshock and Deimling (1984), in a study of 614 families who were caring for an impaired elderly relative, found that 52% of the caregivers reported a negative impact on their relationship with the carereceiver. Using factor analysis, they identified nine items that reflected negative changes in the caregiver/carereceiver relationship. These included the caregiver's feelings of being angry, resentful, depressed, and pressured. Other items described the relationship with the elder as strained with the elder trying to manipulate the caregiver and making more requests than necessary. The researchers developed a weighted sum score of the negative impact on the relationship for each respondent. Using path analysis, they found that the variable having the strongest effect on the relationship was the elder's disruptive behavior. Deimling and Bass (1986) extended this analysis and found that impairment in ability to do the activities of daily living, cognitive incapacity, poor social functioning, and disruptive behavior explained a substantial portion of the overall variance ($\underline{R}^2$=.48) in the negative impact on the caregiver/carereceiver relationship. The strongest direct effects on the relationship, however, resulted from disruptive behavior and poor social functioning.

Whereas almost all studies have identified negative changes, the changes often vary due to individual characteristics of the caregiver. For example, Fitting et al. (1986), in a study of spouse caregivers for Alzheimer's patients, found that more wives reported a deterioration in their marital relationship than husbands. In fact, 25% of the husbands reported an improvement in their relationship with their spouse. This difference may be due to the husband's satisfaction with being able to assume a nurturing role after retirement, whereas, the wife may resent having to continue a caregiving role after many years of nurturing children. Age may also be a factor in determining the level of satisfaction with the caregiving role. Fitting et al. (1986) found younger caregivers were more resentful of their role than were older caregivers.

Impact on Emotional and Physical Health

Researchers have established the emotional and physical strain that caregiving incurs. Over time, this strain leads to deterioration in the caregiver's health. Snyder and Keefe (1985), in a survey of 117 primary caregivers, found that most caregivers reported physical and emotional problems due to caregiving which ranged from hypertension and back problems to depression and mental exhaustion. George and Gwyther (1986) studied the well-being of caregivers in four dimensions: physical health, mental health, financial resources, and social participation. They found that, compared to random community samples, caregivers were more likely to experience problems with mental health and social participation.

To summarize, caregiving has been found to impact on the caregiver's life in three major areas. These include disrupting the daily life of the caregiver, producing changes in the relationship between the caregiver and carereceiver that have usually been found to be negative, and producing physical and emotional strains for the caregiver that often result in illness and/or feelings of burden.

Correlates of Caregiver Burden

Researchers have reported variation in the burden experienced by caregivers. In fact, caregivers coping with seemingly similar situations have reported very different perceptions of burden. What determines the level of strain or burden experienced by caregivers?

Impairment of the Carereceiver and Type of Assistance Needed

Early researchers of caregiver burden made the assumption that the carereceiver's degree of impairment was responsible for the caregiver's burden. Most research findings have not supported this, however. Zarit et al. (1980) studied the factors contributing to feelings of burden for 29 caregivers of elderly persons with dementia and found that neither the extent of cognitive impairment nor the level of functional impairment were correlated with the perceived level of burden. Fitting et al. (1986), in a study of 54 spouse caregivers for dementia patients, also found no relationship between the severity of dementia and the caregiver's sense of burden. Burden did increase with higher levels of dysfunction when the effects of sex and age of spouse were controlled. George and Gwyther (1986), in a study of 510 family caregivers of demented adults, found that the demented member's illness characteristics were minimally related to caregiver well-being, but illness duration was unrelated to caregiver well-being.

Deimling and Bass (1986) expanded the symptoms of mental impairment to include problems in the elderly member's social functioning and the presence of disruptive behavior. Using path analysis, they found that cognitive incapacity had a less important direct effect on caregiver stress than disruptive behavior and impaired social functioning. Cognitive incapacity did have an indirect effect, however, through its influence on disruptive behavior and social functioning.

Although the impairment of the dependent member does not appear to determine the level of caregiver burden, the tasks that the caregiver must perform as result of this impairment have been found to correlate with the level of burden. Montgomery et al. (1985), in a study of 80 caregivers of elderly family members who were currently receiving or had formerly received chore services, found objective burden in caregiving was related to the type of tasks performed. The tasks that involved personal care and bodily contact were correlated with higher levels of perceived burden, whereas the more impersonal tasks such as shopping, doing laundry, and housecleaning were not. Tasks that confined the caregiver in terms of time schedules and/or geographic location were found to be better predictors of objective burden than were the frequency or length of time that a family member provided care.

Chenoweth and Spencer (1986) found that the problem most often reported by caregivers was the need of the elderly member for complete physical care and/or constant supervision (reported by 25%). Many caregivers who must provide extensive physical care over long periods of time do not see this as a burden, however. Could this be due to the relationship between the caregiver and the carereceiver?

Centrality of the Caregiver/Carereceiver Relationship

Cantor (1983) studied how the caregiving experience affects caregivers' lives and found that the closer the bond between the caregiver and carereceiver the more stressful the caregiving role. George and Gwyther (1986), found that that the relationship between the patient and caregiver was important with spouse caregivers exhibiting lower levels of well-being than children, who also reported lower well-being than other relatives.

George and Gwyther (1986) found that coresidence with the patient was associated with decreased well-being for the caregiver in the areas of mental status, social participation, and financial resources. Although spouses are more likely to be living with the impaired member than adult children, combining households often occurs to prevent or delay institutionalization. Brubaker (1986) proposed that the level of satisfaction in multigenerational households is affected by the costs the family incurs in regard to disruption in family routines or completion of family tasks. He theorized that a number of factors interrelate to determine the level of satisfaction and/or stress within households. These factors include: structural factors such as gender of members, family composition, and social class; individual family member characteristics, such as type of dependency, filial maturity, and attitudes toward aging; family factors such as past coping skills, and the history of intrafamily relationships; and community resources. His conceptual model identified important variables that should be included in future research.

Social Supports Available to the Caregiver

Research findings have usually demonstrated the importance of informal social supports in reducing caregiver burden. Zarit et al. (1980) found informal social support, as measured by the frequency of family visits, to be significantly related to the level of caregiver burden with respondents who received more visits from children, grandchildren, and siblings reporting less burden. Supporting these findings was George and Gwyther's (1986) study which showed that caregivers who perceived the need for increased social support reported lower levels of well-being.

Research findings about the influence of formal supports on caregiver burden have not supported their being an important mediator. Hooyman et al. (1985) compared the burden of caregivers in families in which chore service was being received and families in which it had been terminated and found no difference in the burden level of the two groups. We should not conclude that formal supports are unimportant, however. Chenoweth and Spencer (1986) found that family caregivers for Azheimer's patients reported that having a physician available by phone throughout the patient's illness was extremely helpful.

In summary, although the degree of impairment that the elderly person is experiencing usually has not been correlated with caregiver burden, the type of tasks that the caregiver must perform as a result of the disability has been related. Tasks that deal with personal care are usually perceived as most burdensome. The level of burden associated with providing care is influenced by the centrality of the relationship between the caregiver and carereceiver, with spouses and persons sharing the same households experiencing the highest levels of burden. Burden is also related to the social supports available to the caregiver with fairly consistent findings about the importance of informal social supports in mediating burden. Findings about the importance of formal supports have been inconsistent, although the research in this area is limited. These inconsistent reports may be due to the manner in which researchers measure caregiver burden.

Measurement of Caregiver Burden

Preliminary studies, such as those by Brody (1966), Townsend (1968), Shanas, Townsend, Wedderburn, Friis, Milhoj and Stehower (1968), and Shanas (1979), helped to establish that families were not abandoning their elderly relatives. In fact, they were often providing the needed care at great personal cost. Research such as that by Robinson and Thurnher (1979), Fengler (1979), and Brody (1981) helped to identify the burden of this care and the impact of caregiving on spouses and children. The degree or level of burden could not be assessed until researchers developed instruments for measuring burden, however.

Zarit et al. (1980) developed one of the first measurement instruments specifically for assessing caregiver burden. The inventory contains 22 items that cover areas most frequently mentioned by caregivers as problems (e.g., caregiver's health, psychological well-being, finances, social life, and relationship between the caregiver and the impaired person). Caregivers are asked to indicate the extent to which each item describes how they feel on a scale from "not at all" to "extremely". From these responses investigators can calculate a total burden score. Although Zarit et al. (1980) did not report on the empirical testing of the tool, according to Pratt et al. (1985) the Caregiver Strain Scale has a reported alpha reliability coefficient of .79 (Zarit, 1982, cited by Pratt, et al., 1985). The Caregiver Strain Scale made a major contribution to the research of caregiver burden and is the tool after which most measurement instruments have been fashioned.

Robinson (1983) developed a series of questions based on correlates of caregiving burden, and attempted to empirically validate a screening instrument for detecting caregiver strain. From an earlier longitudinal study of 49 adult children who were caregivers for elderly parents, she identified 10 common stressors associated with caregiving (inconvenience, confinement, family adjustments, changes in personal plans, competing demands on time, emotional adjustments, upsetting behavior, the parent seeming to be a different person, work adjustments, and feelings of being completely overwhelmed). From relevant literature three additional items were identified (sleep disturbance, physical strain, and financial strain). These 13 items became the Caregiver Strain Index. Robinson tested the reliability and validity of the instrument in a study of 85 caregivers who were recently hospitalized patients, and were 65 or older. Internal consistency as measured by the Cronbach's alpha estimate was .86. Construct validity was assessed by comparing the results with subjective perceptions of the caretaking relationship and information about the caregiver's emotional status in the areas of depression, anxiety, and hostility. As expected, CSI scores were negatively correlated with the caregiver's perception of the caretaking relationship as being what they had expected. Scores correlated positively with anxiety, depression, and hostility scores as expected.

Poulshock and Deimling (1984) proposed that cross-study comparisons of caregiver burden were difficult because of the diversity in the ways researchers defined and measured burden. Caregiving burden definitions have ranged from burden as emotional costs (Thompson & Doll, 1982) to specific changes in the caregiver's day-to-day life (Fatheringham, Skelton, & Hoddinott, 1972). Other aspects of caregiver burden have included financial strain, role strain, and physical health deterioration (Robinson, 1983; Zarit et al., 1980). According to Poulshock and Deimling, caregiving burden is a multidimensional concept. They proposed that the the objective changes in the caregiver's life be viewed as the impact of caregiving.

This impact should be assessed separately from the caregiver's subjective view that certain tasks performed or certain behaviors of the elder are burdensome. These researchers conceptualized burden as a mediating force between the elder's impairment and the impact on the caregiver. This model helps in explaining why caregivers caring for family members with similar disabilities and requiring similar caregiving tasks may have varying levels of burden.

Thompson and Doll (1982) and Montgomery et al. (1985) conceptualized caregiver burden as being made up of two dichotomous components labeled objective and subjective. Whereas the objective component refers to the disruptions in the family's everyday life, the subjective component refers to the feelings, attitudes, and emotions connected to caregiving. Montgomery et al. (1985) found that different factors are related to subjective burden than are related to objective burden. They found that the best predictors of subjective burden were age and income of the caregiver, whereas the best predictors of objective burden were caregiving tasks that confine the caregiver either temporally or geographically. These researchers developed separate tools for measurement of subjective and objective burden which are discussed further in the section on measurement. This conceptualization and operationalization of caregiver burden should help to make the results of future research clearer.

Montgomery et al. (1985) proposed that the inconsistent findings about burden may be due to differences in definitions and measurement of both the extent of caregiving and the consequences of caregiving. They pointed out that, in most studies, both the conceptual and operational definition of the extent of caregiving have been confined to the total number of tasks performed and/or the number of hours spent performing caregiving tasks. As discussed earlier, the extent of caregiving is also influenced by the type of tasks that must be performed. In studies where researchers moved beyond the total number of tasks and addressed the consequences of performing certain tasks, the analysis was usually confined to single-item measures and provided little insight into the quality of the tasks that are related to burden or strain.

The consequences of caregiving have been referred to as burden, caregiver stress, problems, caregiver strain and adverse effects in various studies (e.g., Robinson, 1983; Zarit et al., 1980). Montgomery et al. (1985) proposed that studies failed in conceptualizing consequences of caregiving when they used inventories that combined both events or happenings and attitudes or emotions in assessing caregiver burden.

To summarize, research on the experience of caregiving has evolved from the identification of the correlates of burden to the measurement of the level or degree of burden. Poulshock and Deimling (1984) and Montgomery et al. (1985) identified problems with conceptualizations and definitions of caregiver burden that lead to imprecision in measurement and lack of consistency in findings. They developed a dichotomous conceptualization of burden that should lead to more precision in measuring caregiver burden.

Coping with the Strain of Caregiving

The number of studies in which researchers have examined the strategies that caregivers use in coping with the strains of caregiving is limited. Johnson and Catalano (1983) identified tension-reducing mechanisms that caregivers used in adapting to the burdens of care. These were (a) distancing techniques in which the caregiver decreases support by establishing greater physical and/or psychological distance, and (b) enmeshing techniques in which the caregiver decreases other role involvements and outside contacts in order to care for the ill member. Lost roles are replaced by the caregiving one which often gives new meaning to life. Children were more likely to use distancing techniques while spouses were more likely to use enmeshing techniques.

Strong (1984), in a qualitative study of 10 American Indian and 10 white caregivers of elderly relatives, explored how families view their caregiving situations and compared the types of coping strategies used. She found that the cultural background influenced both the interpretation of events and the subsequent coping strategies. The major difference between Indian and white respondents was that Indian caretakers more often reported the use of stress management strategies, especially passive forbearance, than did their white counterparts.

Pratt et al. (1985) examined the relationship of coping strategies used by 240 caregivers of Alzheimer's disease patients to the caregiver's subjective sense of burden. They used Zarit et al.'s (1980) Caregiver Burden Scale to measure burden and McCubbin et al.'s (1981) Family Crisis-Oriented Personal Evaluation Scale (F-COPES) to identify the coping strategies used by caregivers. Three internal coping strategies (confidence in problem-solving, reframing the problem, and passivity) and two external coping strategies (spiritual support and extended family) were significantly related to caregiver burden. Confidence in problem-solving, reframing the problem, spiritual support, and the support of extended family members were correlated with lower burden scores. Passivity, however, was correlated with higher burden scores. Although this study makes a substantial contribution to the study of caregiver coping, readers must interpret the findings cautiously because the sample may have been biased by being composed of caregivers who were seeking advice and support on the management of their relatives with Alzheimer's disease. Also, the research team conceptualized and measured caregiver burden in a unidimensional manner.

In summary, although the research on coping strategies used by caregivers for the elderly is limited, findings indicate that the strategies chosen by caregivers vary by their relationship to the carereceiver. Spouses tend to use enmeshment techniques in which role involvements and outside activities are decreased or replaced by the caregiving role. Children tend to use distancing techniques more often than spouses. The cultural background of caregivers can also influence the strategies used to deal with problems. Pratt et al.'s (1985) study is significant because it examined the relationship between the coping strategies used by caregivers and subjective burden. This study extended this exploration. In order to understand how caregivers cope it is important to look at the theoretical development of the concept of coping.

Theoretical Foundations of Coping Research

Overview of the Concept of Coping

The initial conceptualization of coping was included in Reuben

Hill's ABCX model of crisis (1949). His research on war-induced separations and reunions provided the basic framework for studying family crisis. Hill identified a roller-coaster type of adjustment that involved initial disorganization, followed by recovery, and reorganization. According to McCubbin (1979), Hill touched on the concept of coping by identifying families who appeared to do better by "closing rank."

Lazarus (1961) was one of the first researchers to use the term coping as specific to stress and as encompassing any problem or mastery effort (whether realistic or pathological). Although most researchers assumed that coping followed a situation of threat or harm, Lazaras proposed that a great deal of coping also precedes the emotional arousal and is, in fact, anticipatory. In a later publication (1976), he identified two categories of coping responses, direct actions and palliation. Direct actions are behaviors directed at dealing with harm, threat, or challenge. The behaviors are aimed at altering the person's relationship with the environment. Palliative efforts are those directed at reducing, eliminating, or tolerating the distressing bodily, motor, or affective features of stress.

Folkman and Lazarus (1980) defined coping as referring to the cognitive and behavioral efforts to master, reduce or tolerate the internal and external demands that are created by a stressful transaction. They expanded Lazarus's bidimensional formulation of coping to problem-focused versus emotion-focused coping. The major function of problem-focused coping strategies is to manage the problem that is causing the distress. The major function of emotion-focused coping strategies is to regulate the emotions or distress. Folkman and Lazarus have shown that people use both forms of coping in most stressful encounters. The relative proportion of each form will vary, however, depending on whether the person appaises the situation as holding the potential for control or as not amenable to control.

Pearlin and Schooler (1978) helped to establish the importance of coping research and theory with their publication of "The Structure of Coping." Whereas earlier researchers had viewed non-normative events as capable of producing stress while normative events usually did not, these researchers demonstrated that normative life events, as well as non-normative events, are capable of causing stress. They defined coping as the things people do to avoid being harmed by life strains, and life strains as those enduring problems that have the potential for arousing threat. They saw strain and stressor as interchangeable concepts.

Pearlin and Schooler (1978) discussed the importance of distinguishing between social resources, psychological resources, and specific coping responses. Social resources are interpersonal networks of people who are potentially capable of giving support. Psychological resources are personality characteristics that people can draw upon to help withstand threats. They include the characteristics self-esteem, self-denigration, and mastery. Coping responses are the behaviors, cognitions, and perceptions in which people engage when dealing with life problems.

Pearlin and Schooler identified three types of coping responses. These included (a) responses that modify the situation such as negotiation and seeking advice, (b) responses that function to control the meaning of the problem, such as positive comparisons, selective ignoring, and substitution of rewards or devaluation, and (c) responses that function more for the control of stress itself after it has emerged, such as emotional discharge versus controlled reflectiveness, passive forebearance versus self-assertion, potency versus helplessness, resignation, and optimistic faith in the future.

Like Pearlin and Schooler, Menaghan (1982) also discussed the importance of identifying the difference between coping resources and coping efforts. She expanded Pearlin and Schooler's definition of coping resources to include generalized attitudes and skills such as attitudes about self (esteem and ego strength), attitudes about the world (sense of coherence and belief of mastery), intellectual skills (cognitive flexibility and complexity, analytic abilities, and knowledge), and interpersonal skills (communicating skills, competence, and ease in interpersonal interactions). Coping efforts are covert or overt actions taken in specific situations that are intended to reduce a given problem or stress. Menaghan added a third variable that is also crucial, that of coping style. She defined coping styles as typical, habitual preferences for ways of approaching problems such as a tendency to withdraw versus a tendency to move closer to other people, denial of difficulties versus dwelling on them, activity versus reactivity, or blaming others versus blaming oneself.

McCubbin and Patterson (1983) were probably the first researchers to include the concept of coping in a conceptual model of adjustment and adaptation. In the Double ABCX Model, they extended Hill's crisis theory by identifying factors in the post-crisis period that influence adaptation. They found that coping efforts following a crisis were directed at multiple stressors and strains simultaneously and concluded that coping is not stressor-specific but involves efforts to manage various dimensions of family life at the same time. The family's adaptative coping is an interaction of resources, perceptions, and behavior. Coping efforts are directed at (a) eliminating and/or avoiding stressors and strains, (b) managing the hardships of the situation, (c) maintaining the family system's integrity and morale, (d) acquiring and developing resources to meet demands, and/or (e) implementing structural changes in the family system to accomodate the new demands.

To summarize, the concept of coping has evolved from being viewed as a way of successfully managing stressful non-normative events to being viewed as what people do to manage hardships and life strains. Normative, as well as non-normative events, are capable of producing hardships and stress. Pearlin and Schooler (1978) and Menaghan (1982) furthered research in the field by distinguishing between coping resources and actual coping responses. Menaghan distinguished between these variables and the concept of coping styles. McCubbin and Patterson helped to consolidate this theoretical development by adding the concept of coping in their Double ABCX Model of adjustment and adaptation.

Overview of the Measurement of Coping Effectiveness

Early researchers of coping, such as Menninger (1963) and Haan (1977) viewed coping as successful or healthy ways of dealing with stressful situations. Coping implied managing or succeeding, whereas the use of strategies that did not address the problem itself, such as denial or suppression, reflected failure to cope. Folkman (1984) proposed that coping refers to efforts to manage demands, independent of the outcome. Pearlin and Schooler (1978) also did not view the use of any particular coping response as either appropriate or pathological and did not judge a response's effectiveness solely on how well it purged problems and hardships. Rather they judged effectiveness or efficacy on how well the coping response prevented hardships from resulting in emotional stress. They hypothesized that it was because of variations in coping efficacy that people exposed to similar life strains experienced quite different levels of stress.

Pearlin and Schooler demonstrated that some coping responses were more effective in some role areas than in others. For example, in occupational and economic areas, the most effective type of coping responses involved the manipulation of goals and values, and keeping work in a place of secondary importance. In marriage and parenthood, however, the most effective coping responses were those that eschewed avoidance or withdrawal. Whereas problems in family relationships were less likely to result in stress when people remained committed to and involved in the relationship, problems in matters of work and money were less likely to result in stress when people disengaged themselves from involvement. Pearlin and Schooler concluded that the use of a wide variety of coping mechanisms was most effective in reducing responses to life strains and that there are differences in the types of responses chosen in regard to sex, age, education, and income.

Researchers have taken Pearlin and Schooler's formulation of coping and studied the effectiveness of different coping strategies in reducing stress. For example, Billings and Moos (1981) looked at the effectiveness of active behavioral, active cognitive, and avoidance-oriented coping strategies in reducing stress. They found that, although they could not identify consistently positive or negative types of coping, some strategies were more effective than others. More reliance on active attempts to deal with an event and fewer attempts to avoid dealing with it were associated with less stress. Also, like Pearlin and Schooler, they found that the use of the effective coping strategies occurred more frequently among those persons with higher levels of education and income.

Researchers have also looked at the effectiveness of the use of coping strategies in particular areas of like. For example, Menaghan (1982) focused on measuring coping effectiveness in dealing with marital problems. She studied the effectiveness of four coping efforts: negotiation, optimistic comparison, selective ignoring, and resignation. Effectiveness was measured by the ability of the effort to reduce feelings of distress and its positive role in reducing later problems. Although respondents reported all four coping efforts as subjectively helpful strategies, selective ignoring and resignation actually increased ongoing distress and had little direct impact on later problem levels. Negotiation, although it did not reduce feelings of distress, was associated with fewer problems later. Optimistic comparison was associated with lower distress and fewer later problems. Menagan found that negotiation and optimistic comparisons were less effective for individuals from lower occupational prestige categories and with lower family incomes. Menaghan's findings also suggest a spiral effect in that as problems mount, typical coping choices may actually exacerbate distress.

In conclusion, Pearlin and Schooler (1978) and Folkman (1984) made major contributions to research in the field of coping by conceptualizing coping as encompassing a wide variety of behaviors and proposing that investigators should not judge the effectiveness of coping responses by how they purge problems. Rather, effective coping responses are those that keep problems or hardships from resulting in emotional stress. Their publications helped other researchers to operationalize the measurement of coping efficacy and stimulated research on the effectiveness of particular coping strategies in general and specific problem areas. My research expanded this exploration by studying the coping patterns of caregivers for the elderly and the ability of those coping patterns to reduce caregiver burden.

Chapter III: Methods

Theoretical Framework of the Study

I used the Double ABCX Model of Adjustment and Adaptation by McCubbin and Patterson (1983) as the theoretical model for studying caregiver burden and coping. In this model, the primary caregiver's family is an open system with all members being influenced by change originating either internally or externally. I needed a broad definition of family because many caregivers for the elderly do not actually live in the home of the carereceiver and many are middle-aged persons who are "sandwiched" (Brody, 1981; Miller, 1981) between commitments to and responsibilities for both their elderly parents and their offspring. I adapted a definition from McCubbin and associates (1981): Family means a group of two or more persons related by blood, marriage, or adoption and includes persons who live with the caregiver as well as other persons to whom the caregiver has a long term commitment.

Whereas most studies of caregiving have focused on the burden and negative effects of caregiving (e.g., Robinson & Thurnher, 1979; Zarit et al., 1980), in this study I conceptualized caregiving as providing positive and negative experiences for the caregiver. Caregiving has the potential for producing strain, escalating family conflicts, and impairing the caregiver's health. It also has the potential for enhancing the caregiver's and caregiving family's life by providing a new role for family members, an opportunity to become united in a common commitment, and the opportunity to resolve past conflicts or common commitment, and the opportunity to resolve past conflicts or misunderstandings.

McCubbin and Patterson (1983) defined a stressor as "...a life event or transition impacting upon the family unit which produces, or has the potential for producing, change in the family social system" (p. 8). These changes in the family may be in various areas such as in its boundaries, patterns of interaction, roles, goals, or values. They defined hardships as those demands on the family specifically associated with the stressor event. In this study, the stressor event was the need to provide care for the impaired elderly member, as demonstrated in Figure 2. If the existing family resources are inadequate and/or the family perceives they are unable to provide the needed care a crisis or potential crisis situation occurs. In this study, most of the families were not in a crisis but many had experienced a crisis in the past which resulted in their reaching out to formal support systems such as a home health agency for assistance.

McCubbin and Patterson (1983) added the concept of pile up to their model based on their research with families responding to having a husband/father being held captive or unaccounted for in the Vietnam War (1982). They found that families seldom dealt with only one stressor, but rather, experienced a pile up of stressors and strains. Five broad types of stressors and strains contributed to pile up. These included (a) the initial stressor and its hardships, (b) normative transitions, (c) prior strains, (d) the consequences of family efforts to cope, and (e) ambiguity, both within the family and socially. The present study assessed the pile up of strains in the

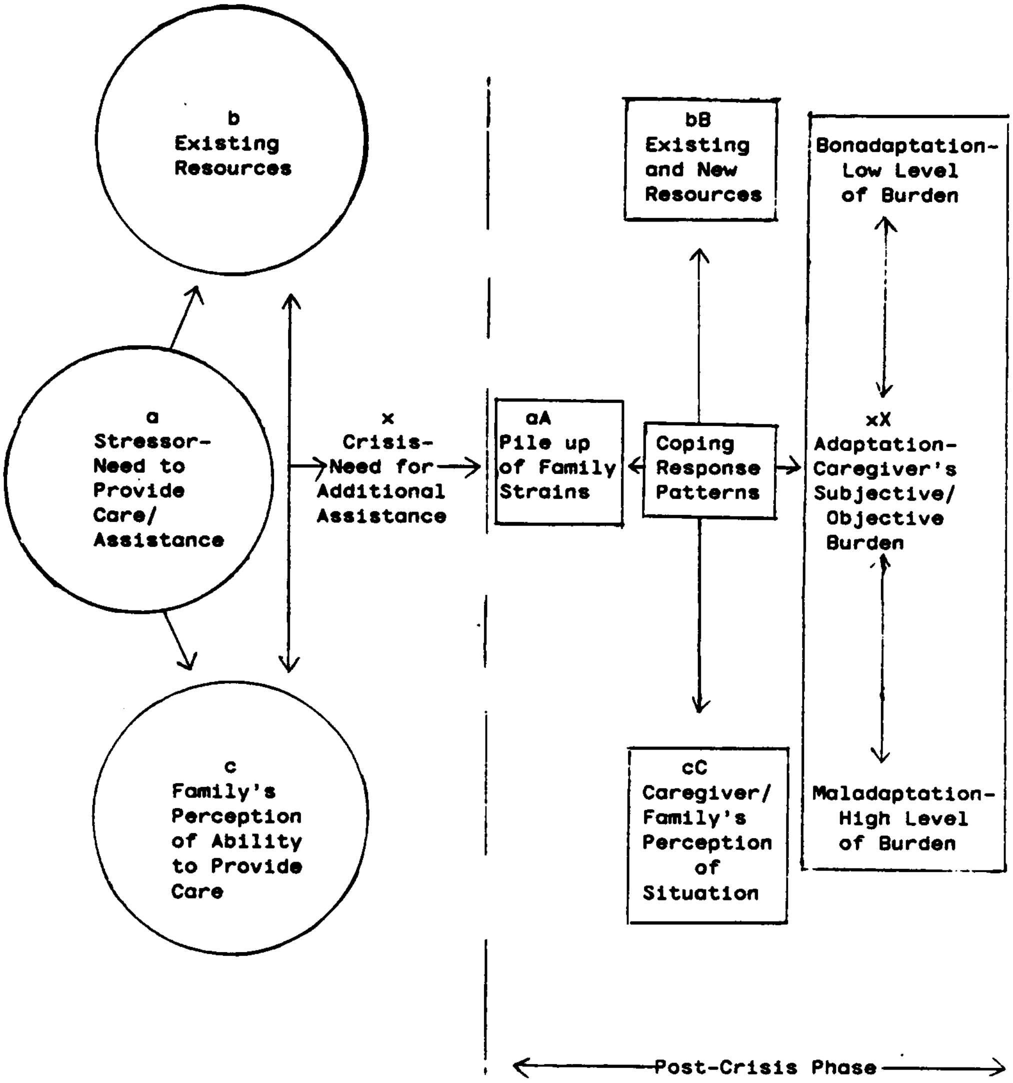

Figure 2: Conceptual Model of the Study Using the Double ABCX Model

caregiver's life by looking at the potentially stressful events that occurred in the caregiver's family during the past year.

The family's resources help to determine its capabilities for meeting the needs of individual members, including the impaired elder's needs. The questionnaire solicited information about the family's financial resources and the sources of assistance from family members and other informal sources of support.

McCubbin and Patterson (1983) viewed coping as a bridging concept with both cognitive and behavioral components wherein resources, perceptions, and behavioral responses interact as the family attempts to achieve a balance in functioning. Family members may direct coping efforts at eliminating or avoiding stressors and strains, managing the hardships or the situation, maintaining the family system's integrity and morale, acquiring and developing resources to meet demands, and implementing structural changes in the family system in order to accommodate the new demands (McCubbin, 1979). They direct coping efforts at multiple stressors and strains simultaneously. In the present study, I assumed that the patterns of coping responses used by the primary caregiver to deal with caring for the elderly member would influence the pile up of other stressors in the family, the resources available to family members, and the caregiver's perception of the situation.

The outcome variable in the Double ABCX Model is the concept of family adaptation (McCubbin & Patterson, 1983). Adaptation is a continuum of outcomes from bonadaptation on the positive end to maladaptation on the negative end. In bonadaptation, the family is able to maintain or strengthen family integrity, continue promoting both member development and family unit development, and maintain family independence and its sense of control over the environment. Maladaptation, on the other hand, represents a continued imbalance in family functioning with deterioration in family integrity, curtailment or deterioration in the personal health and development of a member or the well-being of the family unit, or loss or decline in family independence and autonomy. In this study, I assessed adaptation by examining the caregiver's objective and subjective burden related to caregiving. The hypothesis was that if family members chose coping strategies that were bonadaptive, the primary caregiver's objective and subjective burden would be low.

In summary, the theoretical model in this study is the Double ABCX Model, which defined the relationship between family strains or pile up, coping response patterns, and the primary caregiver's level of subjective and objective burden.

Design

I conducted a mail survey of caregivers using the Dillman Total Design Method (1978). Dillman developed specific guidelines for designing and administering surveys. By carefully following these guidelines, investigators avoid many of the pitfalls in survey research which have resulted in inadequate response rates in the past. The Procedures section contains further details. The questionnaire (Appendix A) provided information about the independent and dependent variables. The independent variables were caregiver/family demographic data, family strains, and coping response patterns. The dependent variables were the caregiver's objective and subjective burden.

Measurement

The assessment tools that I used appear in Appendix A. All have been published previously and I have obtained permission to use them from the developers. The tool for caregiving burden was the Measurement of Subjective Burden and the Measurement of Objective Burden developed by Montgomery et al. (1985). The Measurement of Objective Burden consists of nine items in which respondents report the extent to which their caregiving behaviors have changed their lives. Previous research (Circelli, 1981; Horowitz & Dobrof, 1982; Robinson & Thurnher, 1979; Zarit et al., 1980) has shown that these nine areas are frequently affected by the caregiving experience. The nine areas include amount of time for oneself, amount of privacy, amount of money, amount of personal freedom, amount of energy, amount of time to spend in recreational/social activities, amount of vacational activities, the caregiver's relationships with other family members, and the caregiver's health. Response options, as developed by Montgomery et al. (1985) are 1=a lot more or better, 2=a little more or better, 3=the same, 4=a little less or worse, and 5=a lot less or worse. Chronbach's alpha estimate of reliability for this instrument was .85 (Montgomery et al., 1985).

The Measurement of Subjective Burden consists of 13 items adapted by Montgomery et al. (1985) from Zarit et al.'s (1980) 29-item inventory relating to attitudes and feelings about caregiving. Respondents indicate how often they experience such feelings as pain in watching their relative age, fear about what the future holds, strain in their relationship with the elder, guilt about the relationship and not doing as much for the relative as she or he should, and depression and nervousness as a result of the relationship with the relative. Other questions deal with how the caregiver feels about the way the carereceiver treats him or her. Examples include whether the relative tries to manipulate, makes excessive requests or demands, does not appreciate the caregiver's efforts, or seems to expect the caregiver to act as if she or he were the only one who is dependable. Three items inquire about the positive feelings the caregiver has about the caregiving situation such as feeling useful, contributing to the well-being of the relative, and being pleased with the relationship. In Montgomery et al.'s (1985) tool, the response options are 1=rarely or never, 2=a little of the time, 3=sometimes, 4=often, to 5=most of the time. Chronbach's alpha estimate for this measure was .86 (Montgomery et al.,1985).

Both of the measures of caregiver burden provide a 5-point scale that the respondent uses to indicate how the option applies to his or her situation or feelings. In the objective burden tool, I switched the number of response categories so that a low number would accompany the heading "A Lot Less" to correspond to the number for the category of "Rarely or Never" in the subjective burden tool. For analysis, I recoded these items to the original categories. Because respondents sometimes have difficulty discriminating between the similarly labeled response categories, in the present study I labeled only the end points of the scale with 1=a lot less or better for objective burden, and rarely or never for subjective burden, and 5=a lot more or worse for objective burden, and most of the time for subjective burden.

I assessed the pile up of life stressors in the caregiver's family with the Family Inventory of Life Events and Changes (FILE) developed by McCubbin et al. (1981). FILE consists of 71 items designed to record the normative and non-normative life events experienced by a family unit in the past year. McCubbin and associates developed this tool to index family stress by looking at the pile-up of life events experienced by the family (the aA factor of the Double ABCX model). FILE also records certain life events experienced prior to the past year that may take longer to adapt to or are chronic in nature and produce a prolonged residue of strain and possible distress. The model views the family from a systems perspective, with what happens to one member affecting the other members to some degree. The overall internal reliability of FILE is .72 (Chronbach's alpha).

McCubbin et al. (1981) used factor analysis to identify nine underlying dimensions of strain in FILE. These are intrafamily strains, marital strains, pregnancy/childbearing strains, finance/business strains, work-family transitions and strains, illness and family care strains, losses, transitions in and out of the family, and strains involving legal matters. They assessed the validity by correlating the scales from FILE with the Family Environment Scale (FES) by Moos and Moos (1976). FILE correlated as predicted with FES; a pile up of life changes was negatively correlated with desirable dimensions of the family environment (cohesion, expressiveness, independence, and organization) and positively correlated with undesirable characteristics of the family environment (conflict and control).

Investigators can obtain a weighted stress score, Total Recent Life Changes, by using FILE. McCubbin et al. (1981) developed standardized weights by having members from 75 families, representing all stages of the life cycle, rate the relative degree of social readjustment that each life event would require. A weighted score of total life change equals the sum of the weights for each change or event that has occurred in the family. The Total Recent Life Change measure correlated with FES as predicted; negatively with the FES dimensions of cohesion, independence, and organization, and positively with conflict. In the present study, respondents indicated whether each event or family change occurred during the past year, and their family strain score was the sum of the standardized weights for each event or change.

To assess the coping response patterns used by primary caregivers to deal with problems and crises, I used the Coping Inventory for Parents (CHIP) with slight modification in wording to make items applicable to caring for an elderly family member rather than a child. McCubbin, McCubbin, Cauble, and Nevin (1979) developed CHIP to assess parents' perceptions of their response to the management of family life when they have a child who is seriously or chronically ill. Although McCubbin and associates (1981) designed CHIP for use in families with an ill child they stated that with slight modification in wording of a few items, it would be applicable to a family situation in which any member was seriously or chronically ill. Although it had not been validated for use with this age group, it was used because no other known tool has been developed and validated for use with caregivers of elderly relatives. CHIP operationalizes the coping dimension of the Double ABCX Model because it assesses the coping strategies used by the caregiver who is attempting to manage family life and adapt to the hardships of having a chronically ill family member.

Factor analysis of responses from 185 parents who had a child with cystic fibrosis indicated that CHIP items identify three coping patterns (McCubbin et al., 1981). Nineteen of the items factored into the coping pattern, "maintaining family integration, cooperation and an optimistic definition of the situation," with a Chronbach's alpha estimate of .79. Eighteen items comprise the pattern, "maintaining social support, self-esteem, and psychological stability," also with a Chronbach's alpha estimate of .79. The coping pattern, "understanding the medical situation through communication with other parents and consultation with medical staff," involved eight items with a .71 Chronbach alpha estimate.

McCubbin and associates (1981) made validity assessments of CHIP using the Family Environment Scale (FES) by Moos and Moos (1976). Mothers who used all three coping patterns were high in cohesiveness and expressiveness. For fathers, use of two coping patterns (maintaining family integration, and gaining an understanding of the medical situation) was associated with cohesiveness, conflict, organization, and control. McCubbin et al. (1981) also performed a discriminant analysis between low conflict and high conflict families who had a child with cerebral palsy. Mothers and fathers in high conflict families reported significantly greater use of all three coping patterns. According to McCubbin et al. (1981), these findings are consistent with the theoretical understanding of coping in the sense that families develop behaviors in response to stressful situations. High conflict in the family is one index of family stress. McCubbin et al. (1981) recommended that investigators examine the scores obtained on CHIP in relation to the type and number of demands placed on the family unit. In situations where many potentially stressful events have occurred, the scores are expected to be high.

Respondents to the CHIP instrument indicate how helpful each of the 45 coping behaviors has been in managing the home illness situation. They rate helpfulness on a scale of 0-3. For coping behaviors that they have never used, respondents check whether they do not cope this way because they do not choose to or because the coping behavior is not possible in their particular situation. In the present study, respondents recorded coping behaviors that they have not used as 0 and they rated helpfulness on a scale from 1 (not helpful) to 4 (very helpful).

I obtained information about the caregiver's perception of the negative and positive effects of caregiving by examining responses to individual items on the Measurement of Subjective Burden and responses to open-ended questions. The assessment of positive benefits included responses to items 2, 5, and 7 of the Measurement of Subjective Burden and to an open-ended statement: "What positive or good things that have happened for you and/or your family as the result of caring for your family member?" The identification of negative aspects of caregiving came from the remaining items on the Measurement of Subjective Burden and an open-ended question: "What negative or bad things have happened for you and/or your family because of caring for your family member?"

I also obtained information about the resources available to the family through questions about the family's income, the sources of informal support, and the formal supports utilized by the family. I collected demographic information about the elderly family member's age, sex, medical diagnoses, functional limitations, mental status, and the assistance that the person needed with different caregiving tasks. Information about the primary caregiver included age, sex, employment status, marital status, years of schooling, relationship to the carereceiver, and self-reported health status.

Procedure and Sample

I sent letters in late December 1987 to directors of six home health agencies (three in Roanoke, Virginia and three in the New River Valley area of Virginia) to request their assistance with contacting participants. The criteria for inclusion in the study were that the respondents were related to and the primary caregiver for a sick or disabled elderly person (60 years of age or older) who was residing in the community. In early January 1988, I met with each director to discuss the planned research and to work out details. It was the consensus of the directors that they could not release addresses of clients and caregivers without the written consent of both parties. Thus, staff members took a letter explaining the study and a consent form (Appendix A) to families who met the eligibility criteria. I gave presentations about the research and how staff members would participate at staff meetings for three agencies. At the other three agencies, the directors preferred to discuss this with agency staff members. I placed a brief summary of the research and eligibility criteria in a folder at each agency for staff members to read.

I conducted a pilot study in January 1988 with a sample of 5 caregivers from the home health agencies. The purpose of the pilot was to gain a general response to the questionnaire, detect ambiguous language, and receive feedback on the length of time needed to complete the items. After analyzing the pilot data, I made changes to simplify the wording of the CHIPS and FILE tools. Some respondents indicated that certain changes and life events on the FILE tool did not apply to them because they were not married or did not have children. Therefore, I added the response choice N.A. for not applicable.

Caregivers in the pilot study indicated that the questionnaire took about 45 minutes to complete and it was over two weeks before most of the completed questionnaires were returned. Nursing personnel commented that the caregivers were somewhat overwhelmed by the size of the questionnaire booklet and the number of questions and needed encouragement to complete it. They also commented that some of the words were above the reading level of many of their caregivers. In order to reduce the size of the questionnaire and reduce the number of items that did not apply to most caregivers, I deleted FILE items with factor loadings of less than .45 except in the area of Illness and Family Care Changes. I retained all items in this area because of their applicability to families with a sick member. All items in the entire questionnaire were examined for ease of understanding and changes were made while attempting to maintain the original meaning of the item. Although the changes made comparison to the findings of McCubbin and others difficult and may have threatened the validity of the instruments, I believe they were necessary in order to make the questionnaire acceptable to respondents. After the revisions, a fifth grade student who had been involved in the home care of sick grandparents completed the questionnaire. She responded appropriately to all items and finished the task in 25 minutes. This confirmed that the reading level of the instrument was not too difficult for the potential respondents.

Staff members collected consents to participate between February 1 and April 15, 1988. Three weeks after the staff members began collecting consents to participate in the study, a large proportion of the consenting caregivers were from the Roanoke area. Home health agencies in the New River Valley indicated that they did not have many eligible caregivers who were willing to be in the study. In an attempt to increase the number of participants in the New River Valley, I made efforts to contact caregivers who were not receiving home health services. I placed notices about the need for participants in two newspapers and a university faculty/staff newsletter. I also sent notices to 13 churches and requested that they publish them in their church bulletins or newsletters. A notice appeared in the newsletter of the Area Agency On Aging. I also solicited participants through brief presentations at an AARP meeting and an Alzheimer's Workshop for family caregivers. Hospice volunteers in the Blacksburg area took letters about the research to caregivers for hospice clients. Twelve caregivers completed questionnaires as result of these efforts.

In an effort to increase the overall sample size, I made attempts to contact caregivers in the Roanoke area who were not receiving home health services. I met with the director of the Adult Day Care Center in Roanoke and explained the study. She offered to give questionnaires to interested caregivers for day care participants at sites in Roanoke and Salem. Thirteen caregivers took questionnaires and 10 completed them. I also met with the director of the Roanoke Memorial Hospital Hospice. Her staff members took letters explaining the study to caregivers. One consented to receive a questionnaire but did not return it. The director of the hospice contacted three caregivers of elderly family members she knew who were not receiving services from any agency. All three of these completed questionnaires. The League of Older Americans included a notice about the research and the need for participants in their newsletter which circulates to elderly persons in Roanoke and the surrounding counties. This notice did not result in any participants.

Data collection began in March, 1988. Appendix A includes the questionnaire and the correspondence with respondents. Each caregiver received a cover letter, questionnaire, and stamped reply envelope by first class mail. One week later, I sent a follow-up/thank you letter to the entire sample. Three weeks later, an agency staff member or I contacted nonresponding caregivers to find out why they had not returned the questionnaire. I offered to visit the caregiver's home and fill out the questionnaire. Two respondents accepted this offer and 10 declined. Several declined to complete the questionnaires because of the hospitalization or death of the carereceiver. Others failed to do so because their health status had declined since consenting to participate. In two situations, we could find no suitable time to meet despite several attempts to do so.

The sample consisted of caregivers for 97 elderly persons. The response rate was 81% (107 questionnaires mailed out, 97 returned). Table 1 provides a breakdown of the caregivers by type of service and location. Seventy-four percent were caregivers for home health clients and 59% were from the Roanoke area.

Data Analysis

First, I calculated frequencies and percentages for the demographic variables, the family strain items, and the coping responses. Next, I calculated Pearson's correlation coefficients between the dependent variables, among the independent variables, and between dependent and independent variables. In order to perform correlation analysis, I recoded several contextual and demographic response categories to make them dichotomous or continuous rather than nominal or ordinal. Race of the caregivers and carereceivers was recoded into 1=nonwhite and 2=white. Marital status was recoded to 1=married and 2=not married. Health status of the caregiver was recoded to 1=good health and 2=poor health. Tasks with which the carereceiver required assistance were recoded to 0=no help needed and 1=help needed. The total assistance needed was the sum of the number of tasks requiring help. The sources of informal support were recoded to 0=no help available and 1=help available. The total amount of informal support was the sum of the sources from which help was available. Where the caregiver and carereceiver lived was coded as 1=in the same home and 2=in separate homes. The total number of health problems was the sum of the carereceiver's main health problem

Table 1

Caregivers by Method of Contact and Location

Method of Contact	Location		Total
	Roanoke	New River District	
Home Health Agencies	44	28	72
Non Home Health:			
Adult Day Care	10	0	10
Other (Hospice, Volunteers, etc.)	3	12	15
Total	57	40	97

and the number of other diagnosed health problems. The total functional limitations experienced by the carereceiver was the sum of the number of limitations present. Mental status was recoded as 1=oriented and 2=disoriented. Location was recoded into two categories by combining the urban and suburban categories with 1=urban/suburban and 2=rural.

It was not possible to create dichotomous or continuous categories for the relationship between the caregiver and carereceiver. Therefore, I recoded the responses into four groups (1=spouse, 2=parent, 3=parent-in-law, and 4=other) and performed analysis of variance to determine whether the groups differed on the dependent variables. The results indicated that none of the groups differed significantly in the mean level of objective burden or subjective burden. Therefore, further analyses did not include this variable.

Because some caregivers were receiving assistance from home health agencies and others were not, I performed a T-Test to determine whether the two groups differed on the dependent variables. Results showed that the groups did not differ significantly on objective burden. They did differ significantly in subjective burden, however, with caregivers receiving home health services having a mean score of 28 on the subjective burden scale and caregivers not receiving home health having a mean score of 36. Subsequent analyses included the presence or absence of home health services as a dichotomus independent variable.

To summarize, the independent variables included in the correlation analysis were (a) the coping response patterns, (b) the caregiving family's strain, (c) the sex, race, age, marital status, years of school, education, employment status, and health of the caregiver, (d) the caregiver's family income, (e) the total number of tasks requiring assistance, (f) the total number of sources of informal support available, (g) the total number of formal supports utilized, (h) the presence of home health services, (i) the number of health problems, (j) the number of functional disabilities, (k) the carereceiver's sex, race, age, and mental status, (l) whether the carereceiver and caregiver lived in the same house, (m) the location of the the carereceiver's residence and (n) the number of months the family received home health services.

The next step in the data analysis was to compute multiple regression equations to assess the relationship between subjective burden or objective burden and the patterns of coping responses and the family's life strain. Subjective and objective burden were each regressed on the three patterns of coping responses, family strain, and the other independent variables with which there were significant zero-order correlations.

Finally, I analyzed the positive and negative aspects of caregiving. I calculated the frequencies and percentages of responses on the subjective burden tool that related to each dimension. I also categorized the responses to open-ended questions about the positive and negative aspects of caregiving into major themes and calculated frequencies.

Limitations of the Study

One limitation of the study is that the caregiver's family situation and coping response patterns prior to assuming the caregiver role were unknown. As I demonstrated in Figure 1, the unique characteristics that the caregiver brings to the caregiving situation influence strains. The feelings of burden that result from coping with caregiving strains, in turn, influence the caregiver's unique characteristics and the ability to provide future care. Longitudinal studies that would assess well-being prior to and at intervals after assuming the caregiver role, would help to identify these relationships.

Coping responses were self-reported rather than observed as the caregivers actively dealt with the problems of caring for their family members. Caregivers may have been biased in their reporting on the helpfulness of the coping responses they used in dealing with problems, and such bias may have interfered with their reporting accurately on what occurred.

Some caregivers, most of whom were middle-aged and elderly, may not have been accustomed to filling out questionnaires and, therefore, did not consent to participate in the study. This limited the study to those who could read and write. To facilitate participation by others, I asked caregivers to indicate whether they needed assistance completing the questionnaire when they signed the consent form. If they did need assistance, I made an appointment and completed the questionnaire.

Because of the need to protect confidentiality, caregivers could not be chosen at random from the entire caseload of cooperating home health agencies but had to be chosen from those consenting to have their name and address released by the home health agency. This may have biased the study toward caregivers who had lower levels of caregiver burden, were more educated, and were more perceptive of the need for research. I made efforts to gain the support of staff nurses so that they would endorse the study and encourage caregivers who might not volunteer to be in the study due to limitations in reading and writing abilities or vision.

Protection of Human Subjects

I obtained a certification of exemption of projects involving human subjects from the authorized reviewer in the Department of Family and Child Development (Appendix B). I did not anticipate any problems with protecting the rights of individuals because respondents indicated their willingness to participate by completing a consent form and providing their names and addresses for mail contact or telephone numbers if they needed assistance in completing the forms. Members of the pilot study also completed a consent statement. The elderly carereceivers signed their consent for information to be obtained from agency records. Respondents who were not receiving home health services indicated their consent by contacting me by phone, or in person, and volunteering to be in the study. The adult day care center director gave questionnaires to family caregivers who expressed interest in the study and verbal consent to participate. Individual questionnaires were identified only by a number. Participants received the telephone number and address of the researcher to contact if problems resulted from completing the questionnaire.

Chapter IV: Results and Discussion

Analysis of the Contextual Variables

The first issue addressed in the data analysis was the context of caregiving. Demographic characteristics of the caregivers and carereceivers, as evidenced by descriptive statistics, supplied the relevant information.

Demographic characteristics of the caregivers.

Most of the caregivers were females (84%) who were caring for their mothers (35%) or husbands (29%)(Table 2). Although the age of caregivers ranged from 26 to 88 years, the mean and median age was 59 years. The largest group (28%) was between age 56 and 65 years of age. The proportion of caregivers who were elderly (over age 65) was considerable (32%), however. The data reflect the current trend toward caregivers becoming older.

The amount of education varied from 6 to 22 years with the median being 12 years (Table 2). Almost one-third (32%) had completed 12 years of education. Twenty-two percent had attended college or another training program. Six percent had advanced graduate degree work. Table 2 demonstrates, however, that persons without a high school education were well represented (38%).

Only 26% of the caregivers were employed (Table 2). Several spoke of having to give up their jobs because of needing to provide care for their relatives. Most (73%) evaluated their own health for the last six months as good or very good. The family yearly income for over one-half (56%) of the caregivers was between $5,001 and $25,000 with the median being in the $15,001 to $25,000 range. Seven

Table 2
Demographic Characteristics of Caregivers

Variable	Frequency	Percentage
Sex		
Female	81	83.5
Male	16	16.5
Race		
Non White	9	9.3
White	88	90.7
Age(Mean=59.3, Median=59.5)		
26-45	14	14.3
46-55	22	22.7
56-65	27	27.9
66-75	21	21.6
75+	10	10.3
Missing	3	3.1
Marital Status		
Married	73	75.3
Widowed	6	6.2
Divorced	11	11.3
Separated	1	1.0
Never Married	6	6.2
Years of School(Mean=11.6, Median=12)		
4-8 Years	18	18.5
9-11 Years	19	19.5
12 Year	31	32.0
13-16 Years	21	21.6
17-22 Years	6	6.1
Missing	2	2.1
Employed		
No	72	74.2
Yes	25	25.8
Caregiver's Self-Reported Health (For the Last Six Months)		
Very Good	16	16.5
Good	55	56.7
Poor	21	21.6
Very Poor	5	5.2

Table 2 (continued)

Variable	Frequency	Percentage
Category of Relationship (Carereceiver is Caregiver's)		
Wife	10	10.3
Husband	29	29.9
Mother	34	35.1
Mother-in-law	9	9.3
Father	7	7.2
Father-in-law	2	2.1
Sister or Brother	1	1.0
Grandparent	3	3.1
Other	2	2.1
Family Income For Last Year(Mean and Median $15,001 to $25,000)		
Less than $5,000	7	7.2
$5,001 to $15,000	35	36.1
$15,001 to$ 25,000	19	19.6
$25,001 to $35,000	9	9.3
$35,001 to $45,000	10	10.3
$45,001 to $55,000	5	5.2
Over $55,001	4	4.5
Missing	8	8.2
Where Carereceiver/Caregiver Live		
In Same Home	91	93.8
In Separate Homes	6	6.2

percent fell below $5,000 and 29% were above $25,000. Most (94%) of the caregivers lived in the same home as the carereceiver.

Demographic characteristics of the carereceivers. More of the carereceivers were women (64%) than men and most (91%) were white. Their ages ranged from 62 to 98 years with the median being 80 years. The data in Table 3 show that the largest proportion (77%) was between 70 and 89 years of age. The majority (68%) of the carereceivers lived in urban or suburban areas. The two health conditions listed most often as the carereceiver's main health problem were urinary problems and stroke. Secondary health problems occurring most frequently were cardiovascular problems, diabetes, stroke, urinary problems, and arthritis (Table 3).

Functional limitations cited most frequently were difficulty with ambulation (79%), reduced endurance (72%) and bowel/bladder incontinence (53%) (Table 3). Over half (63%) of the carereceivers were mentally oriented. One-third (34%) were forgetful, and 28% were disoriented. Only 2% were described as comatose. Several had mental conditions that are often difficult for caregivers to manage. For example, 21% were listed as agitated, and 24% were depressed.

The tasks that required the most assistance from caregivers included handling such daily maintenance activities as laundry, housework, meal preparation, transportation, and assistance with errands (Table 4). Seventy-five percent of the carereceivers required total assistance with taking medication. Over one-half needed total assistance with toileting, bathing, and dressing. One-half needed some type of nursing care. Dealing with money management and personal affairs required total assistance for a majority of the carereceivers.

Table 3
Demographic Characteristics of the Carereceivers

Variable	Frequency	Percentage
Sex		
Female	62	63.9
Male	35	36.1
Race		
Non White	9	9.3
White	88	90.7
Age(Mean=79.6 Median=80)		
62-69 Years	12	12.4
70-79 Years	30	31.0
80-89 Years	45	46.4
90+ Years	10	10.2
Location of Carereceiver		
Urban	47	48.5
Suburban	19	19.6
Rural	31	32.0
Main Health Problem		
Cardiovascular Problems	8	8.3
Anemia	4	4.1
Diabetes	8	8.2
Respiratory Problems	4	4.1
Broken Bones	3	3.1
Liver Disease	1	1.0
Kidney/Urinary Problems	19	19.6
Parkinson's Disease	1	1.0
Stroke/CVA	14	14.4
Alzheimer's Disease	5	5.2
Skin Problems	5	5.2
Cancer	7	7.2
Epilepsy/Seizures	1	1.0
Other	11	11.4
Missing	6	6.2

Table 3 (continued)

Variable	Frequency	Percentage
<u>Other (Secondary) Health Problems</u>		
Heart Condition	35	36.1
Circulation Problems	24	24.7
High Blood Pressure	13	13.4
Anemia	4	4.1
Diabetes	18	18.6
Respiratory Problems	12	12.4
Cataracts	11	11.3
Stomach Ulcers	3	3.1
Broken Bone	3	3.1
Gall Bladder Problems	1	1.0
Hernia	2	2.1
Liver Disease	1	1.0
Kidney Disease	13	13.4
Urinary Problems	15	15.5
Parkinson's Disease	5	5.2
Stroke/CVA	18	18.6
Alzheimer's Disease	7	7.2
Arthritis	17	17.5
Skin Problems	12	12.4
Cancer	8	8.2
Emotional Problems	8	8.2
Memory Problems	11	11.3
Thyroid Problems	4	4.1
Epilepsy/Seizures	2	2.1
Other	27	27.8
<u>Functional Limitations</u>		
Amputation	13	13.4
Bowel/Bladder Incontinence	52	53.6
Contracture	13	13.4
Hearing	36	37.1
Paralysis/Paresis	24	24.7
Endurance	70	72.2
Ambulation	77	79.4
Mental	46	47.4
Speech	32	33.0
Vision	49	50.5
Respiratory	31	32.0
Dependent for all Activities	20	20.6
Other	21	21.6

Table 3 (continued)

Variable	Frequency	Percentage
<u>Mental Status</u>		
Oriented	61	62.9
Forgetful	33	34.0
Disoriented	27	27.8
Agitated	20	20.6
Comatose	2	2.1
Depressed	23	23.7
Lethargic	19	19.6
Other	16	16.5

Table 4

Percentage of Carereceivers Needing Assistance

	Degree of Assistance Needed						
Type of Assistance	No Help 0	1	2	3	4	Total Help 5	Missing
Feeding	34	14	4	7	8	31	1
Toileting	22	4	6	7	8	53	0
Nursing Care	17	8	9	9	6	50	1
Bathing	10	5	4	8	8	63	1
Dressing	12	4	5	12	7	57	2
Bed Transfer	28	6	2	8	4	47	3
Wheelchair Transfer	37	3	1	6	3	37	12
Telephone	27	10	4	5	4	35	13
Money Management	10	6	4	8	2	67	2
Personal Affairs	7	3	7	8	4	68	2
Medications	7	5	3	4	4	76	0
Laundry	3	2	4	2	1	85	0
Meal Preparation	6	2	0	4	3	85	1
Housework	2	2	2	3	4	85	2
Yard Care	6	3	2	3	2	79	4
Walking	15	6	7	12	2	43	13
Transportation	6	0	0	0	2	87	5
Errands	5	1	0	1	2	87	3

There was confusion concerning how to mark the questionnaire when the carereceiver was no longer capable of an activity such as walking, wheelchair, and telephone use. Thus several caregivers did not mark these items.

The sources of informal support varied by the caregiver's situation, especially her or his marital status. Apparently there was some confusion on how to mark the items when the carereceiver was the spouse and many respondents marked items for only the members available without marking "don't have" for missing social network members. Therefore, the reader should interpret results cautiously. One-fourth of the caregivers indicated that they did not have a spouse to help, less than a fifth indicated that their spouse provided a great deal of help, and one-tenth listed the spouse as giving no help (Table 5). The majority of caregivers reported that the carereceiver did not have a spouse available to help. Children provided the most help. Twenty-one percent of the caregivers indicated that their children provided a lot of help. Another 19% evaluated their children's help as moderate. Only 11% reported that their children gave no help.

The informal support provided by the caregiver's siblings was low. Thirty-two percent reported no help from one sibling and 42% reported that no help was provided by several sisters and brothers. Similarly, the carereceiver's siblings, if any, were not involved in providing assistance. Caregivers evaluated the help provided by neighbors, friends, church members, and others as nonexistent (27%) or low to moderate (43%) (Table 5).

Table 5

Sources and Degree of Informal Support to Caregivers(Percentage)

Source of Assistance	Degree of Assistance Provided							
	No Help 0	1	2	3	4	A Lot of Help 5	Don't Have 6	Missing
Caregiver's Spouse	9	4	3	7	6	18	25	28
Caregiver's Child(ren)	10	6	6	19	6	21	27	3
One Sibling	32	7	7	3	4	12	28	10
Several Siblings	42	4	2	5	2	5	28	10
Carereceiver's Spouse	19	2	2	1	2	4	44	25
Carereceiver's Siblings	41	7	6	2	5	6	26	5
Neighbors, Church Members, Friends and Others	27	17	12	14	5	8	10	5

The sources of formal support utilized by carereceivers varied between families as shown in Table 6. Most caregivers reported that their disabled relatives received the services of a family physician. Because most of the families were contacted through home health agencies, the next most frequently reported service was home health services. Two home health agencies were sponsored by health departments. Some of these caregivers marked only one of these services and others marked both. Thirty-four percent reported receiving services from a hospital but there was apparently confusion about whether to mark this item if services were currently being received or were received on the last hospitalization. Small numbers of caregivers listed the other services. Only 1 reported receiving respite care. Respite care services are only available for a limited number of families in Roanoke and not available in the New River Valley. Thirteen reported use of other services and this was usually adult day care.

Analysis of the Main Research Variables

Sources of family strain. One of the major objectives of the study was to identify the pile-up of strain in multiple areas of the caregiving family's life that has the potential for having an impact on the primary caregiver's ability to provide care for the carereceiver. The data in Table 7 illustrate the diversity of changes and events reported by caregivers that are potential sources of stress. The most frequently reported changes or events, however, are those one would expect in a family providing care for a sick member. Sixty-five percent reported an increase in the number of tasks or chores that don't get done, 51% reported increased strain on family

Table 6
Sources of Formal Support

Type of Service	Frequency	Percentage
Family Physician	91	93.8
Medical Specialist	35	36.1
Home Health Agency	69	71.1
Private Sitter	15	15.5
Hospice	4	4.1
Health Department	30	30.9
Social Services Agency	13	13.4
Hospital	34	35.1
Respite Care	1	1.0
Other	13	13.4

money for medical/dental expenses, and 41% reported increased strain on family money for food, clothing, energy, and home care. Fifty-six percent indicated they had experienced increased problems managing a chronically ill or disabled member. Over one-third reported that a member became physically disabled or chronically ill or that a parent or spouse was seriously ill or injured during the last year. Over a fifth reported they had increased responsibility to give care or financial help to their spouse's parents in the last year. Although I did not elicit specific information about the number of relatives the caregiver was caring for, three caregivers said they were caring for more than one relative and several commented that they had earlier cared for another relative.

Thirty percent of the caregivers indicated that someone had experienced emotional problems during the last year. However, we do not know whether this was the caregiver or another member or whether it was related to caregiving or another problem area. During interviews and in written comments several caregivers talked of personal emotional problems they were experiencing (see Table 11).

It is important to note the areas in which caregivers did not report events and changes. Frequencies were low for items dealing with conflict between family members and marital problems. Changes that affected business and work were low. This is understandable because most of the caregivers and their spouses were near retirement or retired. Also most of their children were established in careers, so few reported difficulty managing children or problems with financing education. The percentage reporting deaths in the family was unexpectedly low with the highest percentage being death of close

Table 7
Family Events/Changes in Last 12 Months

Event/Change	Frequency	Percentage	$Weight_a$
Member Had Emotional Problems	29	29.9	58
Increased Conflict Between Husband/Wife	15	15.5	53
Increased Arguments Between Parents/Children	13	13.4	45
Increased Conflict Among Children	12	12.4	48
Increased Difficulty Managing Children	9	9.3	55
Increase In Problems Don't Get Solved	26	26.8	43
Increase In Tasks/Chores Don't Get Done	63	64.9	35
Caregiver or Parent Separated or Divorced	3	3.1	79
Caregiver/Spouse/Parent Had an Affair	3	3.1	68
Increased Problems With Former/Separated Spouse	4	4.1	47
Member Had Unwanted or Difficult Pregnancy	1	1.0	45
Member Gave Birth or Adopted Child	6	6.2	50
Conditions Hurt Family Business	11	11.3	41
Conditions Hurt Family Investments	9	9.3	43
Member Started New Business	3	3.1	50

Table 7 (continued)

Event/Change	Frequency	Percentage	Weight^a
Strain on Money For Medical/Dental Expenses	49	50.5	23
Strain on Money For Food, Clothing, Energy, Home Care	40	41.2	21
Strain of Money For Children's Education	10	10.3	22
Member Started or Returned to Work	8	8.2	41
Member Stopped Working For An Extended Period	19	19.6	51
Member Became Less Satisfied With Job	13	13.4	45
Parent/Spouse Became Seriously Ill or Injured	34	35.1	44
Child Became Seriously Ill or Injured	7	7.2	35
Member Became Physically Disabled or Chronically Ill	34	35.1	73
Problems Managing Chronically Ill or Disabled Member	54	55.7	58
Increased Responsibility to Give Care/Help to Spouse's Parents	22	22.7	47
Member or Close Relative Admitted to Nsg. Home or Institution	7	7.2	44
Parent or Spouse Died	10	10.3	98
Child Member Died	2	2.1	99
Spouse's Parent or Close Relative Died	18	18.6	48
Close Friend of Family Died	27	27.8	47

Table 7 (continued)

Event/Change	Frequency	Percentage	Weight[a]
Son/Daughter was Separated or Divorced	5	5.2	58
Member Broke Up Relationship With Close Friend	4	4.1	35
Member Was Married	9	9.3	42
Young Adult Left Home	11	11.2	43
Young Adult Began College/ Training Program	7	7.2	28
Member Moved Back Home or New Person Moved Into Home	14	14.4	38
Caregiver or Spouse Started School/Training Program	4	4.1	38
Member Went to Jail/ Juvenile Detention	1	1.0	68
Member Picked Up By Police	1	1.0	57
Physical/Sexual Abuse/ Violence in Home	1	1.0	75

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[a] The weights for individual items are based on research by McCubbin et al. (1981) and indicate the relative degree of social readjustment a family must make in its usual pattern of life as a result of experiencing the change or event.

friends of the family. This probably relates to the advanced age of many of the carereceivers. When the spouse was the carereceiver, his or her parents had usually died many years earlier. When a child was caring for a parent, the carereceiver's parents and spouse had usually died over a year earlier. Another area in which events and changes were low was legal violations and domestic violence. Responses to these areas may have been affected by fear of breaks in confidentiality or social desirability response bias. More likely the results reflect that only caregivers in fairly stable home situations consented to be in the study.

Table 7 also shows the weights assigned to specific changes or events that McCubbin et al. (1981) developed and used to derive family strain scores. These standardized weights, based on research with 75 families across the life cycle, indicate the relative degree of social readjustment that each life event would require. A weighted score of total life change equals the sum of the weights for each event or change that has occurred. The summarized score provides an indication of the family's degree of pile up of strains that are potentially stressful. The highest possible score would be 2038 if all changes or events occurred. In this sample, the scores ranged from 0 to 855 with 287 being the mean (n=88). It appears from the summarized scores for this group that the degree of pile up was relatively low. Because no previous researchers have investigated pile up in families caring for elderly members and because I deleted some items after pretesting, it is impossible to make comparisons with similar data sets or draw conclusions about the significance of this mean and range.

Caregiver burden and the positive and negative aspects of caregiving. Most caregivers indicated that caregiving had changed their lifestyles. Over one-half stated they had a lot less time for themselves and a lot less personal freedom (Table 8). About three-fourths responded that caregiving severely reduced their time to spend in social and recreational activities. Most indicated that their relationship with other family members was about the same or had improved, whereas their health status had remained the same or had become worse since they began providing care.

The total objective burden score was the summation of responses after recoding items 1-7 as described in Table 8. The highest level of burden would be a score of 45 and the lowest possible was 9. The scores ranged from 17 to 45 with a mean of 35 (n=97).

Responses to subjective burden items indicated that most caregivers had low levels of negative feelings and high levels of positive feelings (Table 9). Over one-half frequently felt that it was painful to watch their relative age. Forty-two percent indicated that they felt their relative expected them to care for them as if they were the only one the carereceiver could depend on. During private interviews, several caregivers stated that this was true because they actually were the only one available to the carereceiver. Over one-half (62%) indicated that they rarely or never felt that they do not do as much as they could or should for their relative, and 71% rarely or never felt guilty about their relationship with their relative.

The items that dealt with the relationship between the caregiver and carereceiver showed the greatest variation. Although some

Table 8
Caregivers' Objective Burden

	Percentage Reporting Degree of Change							
Dimension	A lot Less 1	2	3	4	A Lot More 5	Missing	Mean	SD
Amount of Time to Self	58	22	13	6	0	1	1.67	.94
Amount of Privacy	35	22	34	3	5	0	2.21	1.12
Amount of Money	34	13	40	6	3	3	2.29	1.11
Amount of Personal Freedom	63	22	8	3	3	1	1.60	.99
Amount of Energy	39	25	31	5	0	1	2.03	.96
Amount of Time For Social/Recreational Activities	67	19	10	3	0	0	1.50	.81
Amount of Vacations/ Trips	74	6	11	2	0	4	1.37	.78
	Better				Worse			
Relationship with Other Members	23	13	40	11	11	0	2.73	1.26
Caregiver's Health	7	11	44	16	21	1	3.31	1.15
Total Objective Burden Score[a]							34.91	5.52

[a] The Total Objective Burden Score was the summation of items after items 1-7 were recoded 1=5, 2=4, 4=3, 5=1. Scores ranged from 17 to 45 (n=97).

Table 9
Caregivers' Subjective Burden

	Percentage Reporting							
Feeling	Rarely/ Never 1	2	3	4	Most/ Always 5	Missing	Mean	SD
Painful to Watch Relative Age	13	9	19	23	35	1	3.57	1.41
Useful in Relationship With Relative	4	4	8	12	72	1	4.43	1.08
Afraid for the Future	28	7	17	21	28	0	3.31	1.59
Strained Relationship With Relative	49	6	21	16	8	1	2.28	1.42
Contributing to Relative's Wellbeing	3	2	2	10	83	0	4.67	.88
Relative Tries To Manipulate/Control	52	10	9	12	17	0	2.32	1.59
Pleased With Relationship With Relative	9	9	13	16	51	2	3.91	1.38
Not Appreciated By Carereceiver As Desired	45	10	16	12	17	1	2.43	1.55
Nervous/Depressed About Relationship With Carereceiver	42	21	18	12	7	0	2.22	1.31
Relative Makes Requests Above What Needs	52	10	12	10	13	2	2.22	1.51
Don't Do As Much For Relative As Could Or Should	63	12	11	6	7	0	1.83	1.28
Relative Expects C.G. to Take Care As If Only One Can Depend On	27	13	9	9	42	1	3.26	1.71
Guilty Over Relationship With Relative	71	10	10	4	4	0	1.60	1.10
Total Subjective Burden Score[a]							29.63	9.61

[a] The Total Subjective Burden was the summation of items after items 2,5,and 7 were recoded to 5=1, 4=2, 2=4, 1=5. Scores ranged from 13 to 56 (n=97).

caregivers indicated that they felt the carereceiver tried to manipulate or control them, did not demonstrate appreciation, or made unreasonable requests, the largest percentage rarely or never felt this way. On the positive side, 71% of the caregivers indicated they felt useful in their relationship with their relative, and 83% believed they were contributing to the well-being of their relative. Fifty-one percent indicated that they were pleased with their relationship with their relative most of the time or always. The others were split along the scale with only 9% indicating that they rarely or never were pleased with the relationship.

The total subjective burden score was also a summation of responses after recoding the positive items as identified in Table 9. The highest level of subjective burden would be indicated by a score of 65 and the lowest by a score of 13. Scores ranged from 13 to 56 with a mean score of 30 (n=97).

I assumed that caregiving contained both positive and negative components or effects for the caregiver. The responses of caregivers to open-ended questions support this contention. Eighty-five (88%) of the respondents wrote answers to the open-ended questions about the positive and negative events and changes that have occurred as result of caregiving. Twenty (24%) of these had only negative comments and 26 (30%) had only positive comments. Thirty-nine (46%) mentioned both positive and negative aspects of caregiving. Tables 10 and 11 display the themes that summarized these comments.

The most frequent comment about the positive consequences of caregiving for the family was that members have become closer as the result of caring for the sick relative (Table 10). Thirteen commented

Table 10
Positive Aspects of Caregiving

Theme	Frequency
Improved Family Relations	
Family Members Have Become Closer	12
Family Stayed Together/Kept Intact	4
Caregiver More Appreciative of Time Spent with Carereceiver	4
Improved Relations Between Caregiver and Carereceiver	3
Family Members Are Working Together	1
Personal Growth and Satisfaction For Caregiver	
Satisfaction That Carereceiver Is Not In A Nursing Home	7
Increased Patience	7
Learning New Skills (esp. Nursing Care)	6
Increased Faith in God	6
Increased Understanding and Compassion	5
Appreciation of Own Ability to Provide Care	4
Personal Fulfillment, Increased Self Respect/ Self Esteem	4
Ability to Meet New People	3
Satisfaction From Improved Health Status/ Progress of Carereceiver	2
More Relaxed	1
Meaningful Role in Life	1
Recognition/Respect From Other Family Members Because of Ability to Provide Care	1
Freedom From Worry About the Quality of Care	1
Lack of Regret/Guilt	1
Awareness of Life and Aging	
Reciprocity Between Generations	4
Increased Appreciation of All People	2
Ability to Teach Children How to Treat/ Respect Older People	1
Increased Awareness of Stages of Life and Acceptance of Death	1
Respect for the Way the Carereceiver Copes	1

Table 10 (continued)

Theme	Frequency
Appreciation of Assistance	
Appreciation of Formal Support Services:	
Home Health Service/Staff	8
Adult Day Care	3
Doctor	1
Medical People in General	1
Awareness/Appreciation of Help/Support:	
From Other People	4
From Neighbors/Friends	3
From Family Members	2
Increased Respect for All Persons Who Care for Sick People	1
Total	106

Table 11
Negative Aspects of Caregiving

Theme	Frequency
Infringements on Lifestyle	
Confinement	17
Lack of Free Time	5
Loss of Independence/Personal Freedom	5
Having to Give Up Employment	5
Inability to Spend Time:	
With Grandchildren	4
With Children	2
With Spouse	1
With Friends	1
Loss/Lack of Privacy	3
Inability to Care For Home As Would Like	1
Personal Effects on Caregiver	
Physical Exhaustion	3
Negative Influence on Health	3
Financial Problems	2
Loss of Interest in Sex	1
Difficulty Showing Affection	1
Stress For Family	
Stress for Caregiver and Spouse	3
Stress From Trying to Keep Home Care and Job Going	2
Stress for Caregiver	1
Negative/Unpleasant Feelings for Caregiver	
Frustration Dealing With Unpleasant/ Uncooperative Behavior of Carereceiver	8
Apprehension/Worry About Caregiver's Future	4
Resentment/Bitterness	2
Anger/Hate Toward Carereceiver	2
Helplessness	1
Guilt	1
Being Used	1
Mental Anguish	1

Table 11 (continued)

Theme	Frequency
Problems With Family Relations	
Increased Difficulty Relating Between Caregiver and Other Family Members	1
Decreased Closeness to Children	1
Arguments Between Family Members	1
Inability of Other Family Members to Cope With Carereceiver's Illness	1
Inadequate Informal Support	
Family Members Don't Help/Visit as Caregiver Would Like	3
Disappointment in Friends	1
Church Members Don't Visit/Help as Caregiver Would Like	1
Inadequate Formal Support	
Frustrations With Limitations on Available Home Services	9
Frustrations With Inadequate Information and Support in Providing Care	3
Decline in Carereceiver's Status	
Watching Decline in Health	1
Role Reversal	1
Total	103

on their appreciation of sources of formal support that assist them in providing care. Seven commented on their satisfaction that their relative could be cared for at home rather than in a nursing home. This supported Chenoweth and Spencer's (1986) and Fitting et al.'s (1986) findings. In this study, however, this improvement in family relationships occurred for a substantial number of the caregivers as evidenced by the response to the Objective Burden item about how the caregiver's relationship with other family members had changed. Over one-third responded that it had improved.

Many caregivers wrote about the positive influence that caregiving had on them personally. Examples of positive influences included increased patience, understanding, and compassion. Several stated that they felt good about having learned new skills and their ability to provide the needed care. Six indicated that caregiving had increased their awareness of or faith in God.

Caregiving made some caregivers more aware of life and the aging process. Four caregivers appreciated the reciprocity between generations and expressed their willingness to provide care because of the assistance they had received earlier from their parents. One younger respondent stated that caregiving had provided an opportunity for her children to learn how to treat and respect older people. One mentioned being more aware of the stages of life and accepting of death. Two stated that they were more appreciative of all people. No known studies have identified positive effects besides those dealing with improved family relationships.

On the negative side, the most frequent comments dealt with the confinement of caregiving and restrictions on time and personal freedom for the caregiver (Table 11). Eight listed their frustrations in dealing with the unpleasant or uncooperative behavior of the carereceiver. Five wrote about their regret or frustration at having to give up outside employment in order to provide the needed care, and four mentioned their apprehension about their own future when their caregiving role is over. Eight identified negative emotions they experienced such as resentment or bitterness, anger or hate, and guilt or being used. One caregiver whose wife was terminally ill with cancer responded with "mental anguish". Six caregivers related the stress that caregiving caused for them and other family members. Two described their stress at trying to juggle their work at home and on the job.

Another area of concern involved available community services. Twelve caregivers indicated frustration with limitations in the formal support services available to assist them. Although no one expressed unhappiness with any of the personnel or agencies providing care, several mentioned their need to receive more assistance. Some felt that government or Medicare policies were unfair in limiting the amount of assistance or the length of time agencies can provide services. Three people indicated their need for more information about providing care and one mentioned how helpful a support group would be if she could be relieved of caregiving to attend. One employed caregiver in the New River Valley area sent a brochure from an adult day care center in another city and spoke of the need for day care in her area.

To summarize, objective burden scores and responses to open-ended questions indicated high levels of burden as the result of infringements on the caregiver's lifestyle. This supports Robinson and Thurnher's (1979), Chenoweth and Spencer's (1986) and Montgomery et al.'s (1985) findings about the confinement of caregiving. On the other hand, subjective burden scores were relatively lower for most caregivers. This difference in the levels of objective and subjective burden agrees with Hoenig and Hamilton's findings (1966, 1969) that the number of caregiving families reporting objective burden was greater than the number reporting subjective burden. Hatfield (1978) and Herz, Endicott, and Spitzer (1976) reported similar findings. Thompson and Doll (1982) found that although the incidence of objective burden was almost identical to the incidence of subjective burden, the proportion of families with severe objective burden was nearly twice the proportion of families with severe subjective burden.

One possible explanation for the difference in the levels of objective and subjective burden in my sample is that most of these families were receiving the services of home health agencies. As stated earlier, those caregivers who were not receiving home health services had a similar mean level of objective burden but a significantly higher mean level of subjective burden (mean=28 for caregivers receiving home health services and mean=36 for caregivers not receiving home health services). It is possible that although home health services as presently mandated by Medicare guidelines cannot address the confinement and infringements on lifestyle that contribute to objective burden, the staff members' support, encouragement, assistance, and counseling about family interaction influences the caregiver's feelings about the caregiving situation and, thus, reduces the subjective burden. The sample of caregivers not receiving home health services was small. Therefore, the reader must make conclusions cautiously. This is a promising area for future research.

<u>Coping patterns</u>. The primary aim of the study was to identify the coping patterns used by family caregivers who are dealing with the strains of caring for a dependent elderly member. Following the recommendations of McCubbin et al. (1981), I divided the coping responses into three categories. Of the strategies that dealt with maintaining family integration, cooperation, and an optimistic definition of the situation, those related to maintaining an optimistic definition of the situation were the most helpful (Table 12). Ninety-two percent of the respondents indicated how helpful their faith in God was in coping with the situation and several mentioned this in their written comments. Believing that the relative was getting the best medical care possible and that all medical workers had their family's best interest in mind were also very helpful. Over three-fourths of the caregivers responded that reminding themselves of the things for which they could be thankful was very helpful. This optimistic definition did not extend to believing that the relative would get better, however. In fact, this belief was the coping response that the largest percentage marked as not helpful.

The coping responses that caregivers most frequently listed as not used were doing things with family relatives and children. Several commented that this was not possible because they did not have any children or close relatives, and others indicated that their relatives and children lived too far away. Most, though, stated that the confinement of

Table 12

Caregivers' Coping Responses That Deal With Maintaining Family Integration, Cooperation, and an Optimistic Definition of the Situation[a]

	Percentage Reporting							
Coping Response	Not Used 0	Not Helpful 1	2	3	Very Helpful 4	Missing	Mean	SD
Keeping Family Life Stable/Normal	10	5	4	22	58	1	3.13	1.33
Trusting Spouse to Support	35	4	5	13	38	3	2.14	1.81
Showing That Strong	10	5	10	20	52	3	3.00	1.35
Getting Other Members To Help With Care	14	14	9	13	49	0	2.67	1.54
Believing Relative Will Get Better	34	21	12	8	25	0	1.69	1.60
Believing Health Workers Have Family's Best Interest In Mind	5	1	2	18	73	1	3.54	.99
Believing In God	2	1	1	4	92	0	3.83	.69
Believing Relative Getting Best Medical Care Possible	3	2	1	11	83	0	3.68	.86
Doing Things With Children	40	7	7	10	32	3	1.86	1.78
Doing Things With Family Relatives	43	8	11	14	21	1	1.58	1.65
Telling Self Much To Be Thankful For	1	1	2	18	78	0	3.71	.66
Encouraging Relative To Be More Independent	28	5	11	18	37	1	2.31	1.67
Building Closer Relationship With Spouse	36	4	8	19	31	2	2.04	1.73

Table 12 (continued)

	Percentage Reporting							
	Not Used	Not Helpful			Very Helpful			
Coping Response	0	1	2	3	4	Missing	Mean	SD
Devoting Self To Relative	4	11	14	23	46	1	2.97	1.21
Talking About Concerns/ Feelings With Spouse	30	5	8	16	39	1	2.27	1.73
Believing Things Will Work Out	4	5	7	18	66	0	3.36	1.09
Having Relative Seen By Doctor	12	7	6	11	62	1	3.04	1.46
Taking Care Of All The Medical Equipment	24	2	4	10	60	0	2.80	1.69
Total Score[b]							49.18	10.69

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[a] Scale developed by McCubbin et al. (1981) with minor modifications to accomodate caregiving for elderly family member rather than children.

[b] Total Score was the summation of responses on items. Total Scores ranged from 4.0 to 72.0.(n=97)

Table 13

Coping Responses Dealing With Maintaining Social Support, Self Esteem, and Psychological Stability[a]

	Percentage Reporting							
Coping Response	Not Used 0	Not Helpful 1	2	3	Very Helpful 4	Missing	Mean	SD
Going Out With Spouse	55	7	5	8	23	2	1.36	1.71
Being With People Who Make Feel Important	7	3	7	20	61	2	3.263	1.20
Working At Outside Job	66	3	6	6	18	1	1.05	1.61
Working Hard At Job	52	4	3	10	29	2	1.60	1.82
Buying Gifts For Self Or Family Members	34	10	8	20	26	2	1.93	1.66
Sleeping	17	8	19	22	42	2	2.66	1.51
Eating	12	11	14	20	42	0	2.68	1.43
Getting Away By Self	28	6	5	18	43	0	2.42	1.71
Building Close Relationships With Others	13	4	16	26	41	1	2.76	1.38
Developing Self As Person	19	5	5	19	52	2	2.79	1.57
Keeping Self In Shape/ Well Groomed	6	3	13	22	55	1	3.17	1.17
Having Friends Visit	12	8	10	17	53	0	2.89	1.44
Becoming More Self Reliant/Independent	14	3	8	18	54	3	2.96	1.46
Spending Time On Hobbies	29	8	12	9	37	4	2.18	1.71
Doing Things With Friends	27	8	8	24	32	1	2.26	1.63
Allowing Self To Get Angry	14	30	19	13	24	0	2.02	1.41
Talking About Feelings	14	4	10	20	52	0	2.89	1.45

Table 13 (continued)

	Percentage Reporting							
Coping Response	Not Used 0	Not Helpful 1	2	3	Very Helpful 4	Missing	Mean	SD
Getting Away From Care Tasks/Responsibilities	12	7	10	8	62	0	3.00	1.47
Total Score[b]							43.33	13.05

[a] Scale developed by McCubbin et al. (1981) with minor modifications to accomodate caregiving for elderly family members rather than children.

[b] Total Score was the summation of responses on items. Total Scores ranged from 0 to 72.0 (n=97).

caregiving prevented them from doing things with their children or relatives.

Table 13 summarizes the coping responses that concern the maintenance of social support, self-esteem, and psychological stability. The responses indicate that getting away from home care tasks and responsibilities, and being with people who make them feel important and appreciated, were very helpful for the largest percentage of caregivers. Over one-half stated that having friends visit was helpful. Self-development activities such as keeping oneself in shape and well-groomed, and becoming more self-reliant and independent were helpful to most respondents. The majority also rated talking about their feelings as being very helpful.

The response evaluated as not helpful by the highest percentage of caregivers was allowing oneself to get angry. Among the responses not used by large percentages of caregivers were those dealing with outside employment and going out with the spouse. For many, working outside the home and going out with the spouse were not possible due to the necessity to stay at home with the carereceiver. For others, going out with the spouse was not possible because the spouse was the carereceiver who was too limited in function to go outside the home. Nonetheless, most of those who used this response found it very helpful in dealing with their problems and feelings.

The largest percentage of caregivers rated all coping responses that dealt with understanding the medical situation through communication with other caregivers and consultation with medical staff as very helpful (see Table 14). Ranking first was being sure medical treatments were done correctly, followed by talking with medical personnel and reading about the medical problem. Even though talking with and reading about other persons in similar situations were very helpful for most who used them, a large percentage did not use these techniques. Some caregivers commented that they did not have such reading materials available to them. Others said they did not know anyone in a similar situation.

In summary, the coping responses reported as very helpful included those that dealt with maintaining an optimistic definition of the situation, especially with the help of religious faith. This agrees with Pratt et al.'s (1985) findings that caregivers use internal coping patterns especially those dealing with reframing the problem and spiritual support. Pratt also found extensive use of coping responses that ellicited support from other family members. My data do not support the use of coping responses that involved other family members. This may be due to the way the measurement tool attempted to assess family support. Although confinement prevents the caregiver from doing things with children and extended family members, a great deal of support may occur through talking with family members. Except for one item on talking with the spouse about feelings and concerns, none elicited information about this type of support from other family members. Getting away from home care tasks and responsibilities and being with people who made the caregiver feel appreciated and important were also very helpful in coping with caregiving.

Believing that the carereceiver was getting the best medical care possible, being sure that all medical treatments were carried out correctly, and having open communication with medical personnel were

Table 14

Coping Responses Dealing With Understanding the Medical Situation Through Communication With Other Caregivers And Consultation With Medical Staff[a]

	Percentage Reporting							
Coping Response	Not Used 0	Not Helpful 1	2	3	Very Helpful 4	Missing	Mean	SD
Talking With The Doctor	7	3	17	14	58	1	3.14	1.24
Talking With Other Medical Personnel	9	2	6	17	66	0	3.28	1.26
Being Sure Medical Treatments Are Done	6	1	4	17	72	1	3.47	1.08
Talking With Others In Similar Situation	16	4	7	20	53	0	2.88	1.50
Reading How People In Similar Situations Manage	20	3	14	18	45	0	2.66	1.55
Telling Friends/Neighbors About Our Situation	11	10	14	25	39	0	2.70	1.38
Reading More About The Medical Problems	11	0	8	20	61	0	3.19	1.30
Total Score[b]							21.24	5.62

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[a] Scale developed by McCubbin et al. (1981) with minor modifications to accomodatte caregiving for elderly family members rather than children.

[b] Total Score was the summation of responses on items. Total Scores ranged from 0 to 28 (*n*=97).

very helpful to caregivers in coping with their situation. Previous studies have not established the importance of formal support in coping with caregiving for the elderly. Perhaps it is not the mere presence of a service that affects coping but rather aspects of that care or the support and assistance provided by individual staff members that is important.

One of the least helpful coping responses was believing that the relative will get better. In most situations, the carereceiver was severely disabled with chronic diseases and recovery was not probable. Not finding this response helpful indicates that caregivers were facing reality rather than using denial. The other response most often reported as not helpful was allowing oneself to get angry. During interviews, several caregivers stated how badly they felt when they let the carereceiver know they were angry. They stated they tried not to display anger because the carereceiver could not help being as he or she was. Expressing anger may also interfere with being able to maintain an optimistic definition of the situation.

Analysis of the Relationships Among Research Variables

Correlation among variables. Following identification of the context of caregiving, the data analysis proceeded as directed by the objectives of the study. First, product moment correlations were performed between the dependent variables. The correlation between objective and subjective burden was not significant ($r=.06$). This indicates that these are separate sources of strain. Although lack of correlation differs with the findings of Montgomery et al. (1985) whose data showed a significant correlation of .34, and Thompson and Doll's findings of Tau=.26 between subjective and objective burden, it supports the conceptualization of subjective and objective burden as dichotomous components of caregiving.

Next I examined the intercorrelation between independent variables to identify possible sources of multicollinearity (Table 15). Although several were significantly correlated, most of the correlations were low ($\underline{r} < .30$). There was moderate correlation ($\underline{r}=-.32$) between family strain and the age of the caregiver. This is reasonable because younger caregivers are more likely to be involved with children and grandchildren and, thus, more likely to experience a greater number of life events and changes. All caregivers and carereceivers were of the same race explaining the correlation ($\underline{r}=1.00$) between these variables.

Functional status was moderately correlated ($\underline{r}=.30$) with mental status. This indicates that as the number of functional limitations increased the patient was more likely to be disoriented.

The level of education, as measured by the number of years the caregiver attended school, was moderately correlated ($\underline{r}=.46$) with family income and marital status of the caregiver ($\underline{r}=.31$). It was negatively correlated ($\underline{r}=-.34$) with the age of the caregiver. The age of the caregiver and the family income were also moderately correlated ($\underline{r}=-.39$). This indicated that younger caregivers were more likely to be married, have higher levels of education, and have greater yearly income. Income was also moderately correlated ($\underline{r}=.34$) with the employment status of the caregiver. The total number of tasks with which the carereceiver needed assistance was negatively correlated ($\underline{r}=-.31$) with employment status. These findings are understandable because as the age of the caregiver increases retirement and living on a fixed and often reduced income commonly occurs. It is also reasonable that as the number of tasks that require assistance go up the ability of the caregiver to maintain outside employment goes down.

The three types of coping patterns were significantly correlated. The highest correlation ($\underline{r}$=.40) was between coping patterns dealing with managing the medical situation and those dealing with maintaining family relations, integration, cooperation, and an optimistic definition of the situation. I concluded that the common variance shared by the three variables is low to moderate, indicating that these are three related but separate dimensions of coping. McCubbin et al. (1981) reported that the CHIP scales were moderately correlated as might be expected because they designed the instrument to assess dimensions of coping behaviors that are related.

Marital status was moderately correlated ($\underline{r}$=-.36) with the coping pattern maintaining family relations, integration, cooperation and an optimistic definition of the situation. It is reasonable that the presence of a spouse would facilitate using these coping responses.

To summarize, the correlation between subjective and objective burden was nonsignificant in contrast to the findings of earlier studies. However, this indicated that the assessment tools were measuring two dichotomous dimensions of caregiver burden. There were low to moderate correlation among the three coping patterns. McCubbin and associates (1981) reported moderate correlation among the scales and attributed this to the dimensions of coping being related even though items factored into three separate dimensions. There was low correlation among the other independent variables that were significantly correlated with the dependent variables, indicating that

Table 15. Intercorrelation Among Independent Variables

Variables	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24
1 Coping Patterns-Family																								
2 Coping Patterns-Support	25																							
3 Coping Patterns-Medical	40	34																						
4 Family Strain	-08	03	03																					
5 Sex-Caregiver	-06	09	-08	-11																				
6 Race-Caregiver	-10	-05	-07	07	05																			
7 Age-Caregiver	16	-24	-09	-32	13	02																		
8 Marital Status-Caregiver	-36	07	01	-03	-13	02	-19																	
9 Years of School	-22	15	00	10	06	-03	-34	31																
10 Employment Status-Caregiver	-06	21	-22	11	12	-06	-33	-06	21															
11 Health-Caregiver	-06	-18	06	22	-14	-05	22	14	-16	-14														
12 Family Income	-13	13	-09	14	06	07	-39	-11	46	34	-18													
13 Total Assistance	-02	-08	24	03	-26	10	-06	16	-02	-31	10	-21												
14 Informal Support	03	-03	-07	20	-02	-09	-09	-22	-06	17	-10	02	16											
15 Total Formal Support	04	-06	08	01	-01	-02	-13	12	-06	04	04	18	01	-11										
16 Home Health Services	17	-19	14	02	01	02	09	-02	-28	-24	-05	-23	10	-15	26									
17 Living Situation	-19	-07	-10	-18	12	08	-11	-15	-15	14	-16	04	-23	16	-10	-20								
18 Sex-Carereceiver	12	-10	-02	-08	-28	-06	39	-18	-17	-10	22	-21	03	00	-17	-17	-01							
19 Race-Carereceiver	-10	-05	-07	07	05	100	02	02	-03	-06	-05	07	10	-09	-02	02	08	-06						
20 Age-Carereceiver	-11	-11	-09	-26	-25	-06	10	23	-10	-10	-02	08	00	-03	00	05	-10	-10	-06					
21 Total Health Problems	-18	04	-06	-15	-11	08	05	10	15	01	-18	-08	-03	-07	-03	02	11	-06	08	07				
22 Mental Status	-12	01	08	-04	-07	20	-28	08	13	00	-08	07	24	04	-05	-05	01	-11	20	04	19			
23 Functional Status	-04	01	06	09	-13	13	-14	20	-09	-19	-01	-01	23	-15	20	35	-12	-13	13	11	17	30		
24 Location	12	03	-03	-05	-13	22	18	-23	-19	05	-07	-13	-05	18	-03	-11	19	22	22	-21	07	-27	-10	
25 Months of Service	16	01	11	-02	06	06	13	-16	-13	-06	05	-17	-09	-12	02	27	-06	-01	06	-13	03	02	13	-02

Note: Decimal points are omitted.

Significant correlations are underlined (P <.05, two tailed) the probability of multicollinearity among independent variables was low. Therefore, analysis of the relationships among the independent variables and the dependent variables proceeded.

Objective 1: To identify whether there are unique characteristics of the primary caregiver and carereceiver that contribute to objective and subjective burden. Objective burden was positively correlated with the health status of the caregiver (r=.38), and the number of tasks with which the carereceiver needed assistance (r=.20) (Table 16). The results indicate that caregivers who have poor health, and have to provide assistance with a larger number of tasks have higher levels of objective burden than caregivers with good health or those who do not have to provide very much assistance with tasks.

Objective burden was negatively correlated with the total sources of informal support (r=-.20). This suggests that caregivers with lower levels of informal support available to them have higher levels of burden and is similar to the results of Zarit et al. (1980). The living situation of caregivers and carereceivers was negatively correlated with objective burden (r=-.29) which indicates that in situations where both live in the same household objective burden is higher. George and Gwyther (1986) reported similar findings. It may be, however, that when the caregiver must attend constantly to the carereceiver, it is necessary for them to live together. The confinement of the caregiver and infringement on lifestyle may be responsible for higher burden rather than the mere fact of living in the same household.

Table 16

Pearson's Correlation of Dependent and Independent Variables

Variables	Objective Burden	Subjective Burden	n_a
Coping P.-Family	-.05	-.07	97
Coping P.-Support	-.07	.13	97
Coping P.-Medical	.18	-.01	97
Family Strain	.30++	.32++	88
Sex-Caregiver	-.08	.07	97
Race-Caregiver	.10	.13	97
Age-Caregiver	.12	-.21+	94
Marital Status	.10	-.08	97
Years of School	.07	.02	95
Employment	-.17	.21+	97
Health-Caregiver	.38++	.09	97
Income	-.17	.16	89
Assistance	.20+	-.03	97
Informal Support	-.20+	-.13	97
Formal Support	.03	.01	97
Home Health Services	.04	-.31++	97
Where Lives	-.29++	.06	97
Age-Carereceiver	-.13	-.18	97
Sex-Carereceiver	.18	-.04	97
Race-Carereceiver	.10	.13	97
Health Problems	.02	-.13	97
Mental Status	.04	-.01	97
Functional Status	.09	-.12	97
Location	-.06	.02	97
Length Service	.09	.04	97

[a] Number of caregivers out of 97 who completed information for each variable.

+*p* <.05, two-tailed.

++*p* <.01, two-tailed.

In stepwise multiple regression analysis, I entered the contextual variables that were significantly correlated with burden along with the coping patterns and the family strain variable. Table 17 indicates that the caregiver's health was the only demographic variable that was significant in explaining objective burden. Although earlier researchers (e.g., Fengler & Goodrich, 1979; Goladetz et al., 1969) reported that caregivers tended to have poor health, no known studies of caregiver burden have identified health of the caregiver as significant in predicting caregiver burden. Cantor (1983) included health of the caregiver as an independent variable in studying the impact of caregiving on the caregiver's life. She did not find health status to be a significant predictor of impact. George and Gwyther (1986) measured physical health status as the number of doctor visits in the last six months and self-reported health. They found that caregivers did not have different physical health than a non-caregiving comparison group. They found, however, that caregivers had more symptoms of poor mental health than the comparison group. Caregivers reported three times as many stress symptoms, and a higher proportion reported using psychotropic drugs. In my study, caregivers were free to define health status as either physical health or both mental and physical health. Therefore, the results may have been different if I had assessed these two areas separately. In future research, including a definition of health or inquiring about these areas separately would help to assess the area of health that most influences objective burden.

Table 17

Stepwise Regression Analysis of Objective Burden

Independent Variable	B	SE B	Beta	R^2	Cumulative R^2
Caregiver's Health	3.8178*	1.1893	.3216	.1381	.1381
Family Strain	.0067*	.0029	.2285	.0477	.1878
Intercept	28.2325	1.6444			
Total				.1878	

Note. Model _F_=7.983, _df_=87, _p_ <.001. Other variables entered into the regression that did not meet the default criteria of the SPSS regression program were the coping pattern dealing with family relations, the coping pattern dealing with social supports, the coping pattern dealing with understanding the medical situation, where the caregiver and carereceiver live, the total sources of informal support and the total number of tasks with which the carereceiver needed assistance.

* $p < .05$.

** $p < .01$.

Subjective burden was positively correlated with the employment status of the caregiver (r=.21) (Table 16). It was negatively correlated with the age of the caregiver (r=-.21). This indicates that younger caregivers who are trying to manage the strains of caregiving and outside employment are likely to have higher levels of subjective burden. Younger caregivers are also more likely to have other roles and responsibilities such as employment and assistance with children and grandchildren. Some are responsible for care for more than one relative, especially parents. This supports Montgomery et al.'s (1985) findings that subjective burden was positively correlated with the caregiver's employment status and negatively correlated with the caregiver's age. Robinson (1983) reported similar relationships.

Whether or not the family was receiving home health services was negatively correlated (r=-.31) with subjective burden. This indicated that caregivers who were receiving assistance through home health services had lower levels of subjective burden. Most studies have measured formal support by measuring the frequency of visits from formal support services or the number of types of formal supports. Hooyman et al.'s (1985) study is one exception. They compared caregivers' burden in families that received in-home chore services and those that had the services terminated. Unlike my results, they found no association between receipt of services and level of caregiver burden. Perhaps chore services are less important than home health services for easing feelings of subjective burden in the caregiving situation.

I performed stepwise multiple regression analysis and included employment status, age of the caregiver, and the presence or absence of home health services along with the coping patterns, and family strain (Table 18). The presence of home health services was the only demographic or contextual variable that was significant in explaining the variance of subjective burden. This differs with Montgomery et al.'s (1985) findings that family income and age of the caregiver were significant in explaining 19% of subjective burden. The findings may be related to the shared variance between family strain and age of the caregiver (r=-.32). Employment status may have been nonsignificant because the zero-order correlation between employment status and the home health services variable was low but significant (r=-.24), indicating some shared variance.

Objective 2: To identify the pile up of strains for the caregiving family that have the potential for impacting on the primary caregiver's ability to provide care for the elderly member and the levels of objective and subjective burden. I performed Pearson's correlation to analyze this relationship (see Table 16). Both objective and subjective burden were positively correlated with family strain. In the stepwise regression analysis described earlier, I entered family strain with the coping patterns and the other independent variables that had significant zero-order correlation with the dependent variables. Family strain contributed signficantly to the explanation of the variance in objective burden (Table 17) and subjective burden (Table 18). Although the degree of total variance (R^2=.19 for objective burden and .21 for subjective burden) explained for both components of caregiver burden is relatively low, it does indicate the importance of family strain in studying caregiver burden.

Table 18
Stepwise Regression Analysis of Subjective Burden

Independent Variable	B	SE B	Beta	R^2	Cumulative R^2
Home Health Services	-7.8287**	2.2010	-.3491	.1153	.1153
Family Strain	.0159**	.0050	.3095	.0957	.2110
Intercept	31.1524	2.4032			
Total				.2110	

Note. Model F=10.966, df=84, p <.01. Other variables entered into the regression that did not meet the default criteria of the SPSS regression program included the coping pattern dealing with family relations, the coping pattern dealing with social supports, the coping pattern dealing with understanding the medical situation, age of the caregiver, and employment status of the caregiver.
**p < .01

Objective 3: To identify the coping response patterns that caregivers have used to manage their problems and crises and to determine the level of subjective and objective burden associated with these coping patterns. None of the three coping patterns were significantly correlated with objective burden at $p < .05$ (Table 8). At $p < .10$, however, the coping pattern that dealt with understanding the medical situation was significant ($r = .18$). Although one must make interpretations cautiously, this may indicate that caregivers with higher levels of objective burden coping find that responses that deal with understanding the medical situation are very helpful.

Subjective burden was not significantly correlated with any of the coping patterns, even at $p < .10$, indicating that caregivers with either high or low levels of burden did not report any particular group of coping responses as helpful (Table 16). Because the levels of subjective burden were relatively low, as reported earlier, this indicates that caregivers with low levels of burden probably have decreased need to use coping responses.

The hypothesis of this study was that if the primary caregiver is using patterns of coping responses that are conducive to positive well-being, the caregiver's subjective and objective burden will be low. These findings do not support this hypothesis. Instead, they indicate that caregivers with high levels of objective burden may perceive coping patterns that deal with understanding the medical situation as helpful. Caregivers with low levels of subjective burden are not likely to perceive the need to use particular coping responses or perceive them as helpful.

Objective 4: To identify whether there is a relationship among the strains experienced, the patterns of coping response employed, and the resulting subjective and objective burden. The multiple regression analyses described earlier assessed the relationship between subjective or objective burden, and the coping response patterns and family life strain. The variables that were significant ($p < .05$) in explaining objective burden were health status of the caregiver and family strain (Table 17). The cumulative R^2 was .19 indicating that this combination of independent variables explained about one fifth of the variance in objective burden. Because the coping pattern, understanding the medical situation, was significant at $p < .10$ and to see if the lack of significance of the coping pattern was due to the loss of power related to the small sample size, I performed stepwise regression analysis with this variable and the other significantly correlated variables in the model but with the probability of F-to-enter at .10. The coping pattern was still not significant in explaining objective burden. Instead, two additional independent variables, informal support and total assistance, became significant in explaining objective burden ($R^2 = .25$).

In assessing the relationship of the variables to subjective burden, only family strain and the presence of home health services significantly contributed to the explanation of subjective burden (Table 18). The R^2 of .21 indicated that this set of independent variables accounted for over one-fifth of the variance in subjective burden.

These findings indicate that there was no relationship between family strains, the coping patterns employed, and the resulting subjective and objective burden in the present sample. We must reject the hypothesis that if caregivers are using patterns of coping responses that are conducive to positive well-being, the caregiver's subjective and objective burden will be lower. Rather, the results indicate that family strains along with other contextual or demographic variables are related to both subjective and objective burden.

In conclusion, this research agrees with earlier findings that subjective and objective burden are two dichotomous dimensions of caregiver burden and that different contextual variables are related to each. Although coping patterns do not appear to be related to either high or low levels of objective or subjective burden, the life events or changes that occur within the caregiving family do influence both areas of caregiving burden. Qualitative as well as quantitative results indicate that caregiving provides positive as well as negative components. Themes identified from caregiver's responses indicate that positive changes and events occur besides just bringing the family closer. Identification of these areas should be helpful in directing future research on the positive components of caregiving.

Chapter V: Summary

Previous research on caregiving for the elderly has shown that caregiving is stressful for most individuals. Few studies have identified the coping strategies used by caregivers. Most researchers have focused on only the primary caregiver rather than the caregiving family. No known studies have looked at the multiple sources of potential strain that occur in the caregiving family. Although many previous findings have identified the negative aspects of caregiving, few have identified the positive aspects and no researchers have studied the balance of costs and rewards incurred in caregiving. This study addressed these gaps in the literature by identifying the multiple strains experienced by caregiving families, the coping patterns used by primary caregivers, and the positive as well as negative aspects of caregiving. The primary objective was to identify the relationship among the strains experienced, the patterns of coping responses employed, and the resulting objective and subjective burden.

Procedure

I conducted a mail survey of family caregivers who were caring for a sick or disabled relative, age 60 years or older. The questionnaire included four instruments previously developed to measure family strain (FILE by McCubbin et al., 1981), coping patterns (CHIP by McCubbin et al., 1979), objective burden (Measurement of Objective Burden by Montgomery et al., 1985), and subjective burden (Measurement of Subjective Burden by Montgomery et al., 1985). After a pretest, I made minor modifications in these tools in order to make the items understandable for persons with reduced reading skills, to eliminate items that did not apply to most caregivers, and to shorten the amount of time needed to complete the questionnaire. I developed additional items to assess the demographic and contextual variables that had been shown to relate to caregiving in previous studies. The questionnaire included two open-ended questions to obtain qualitative data about the positive and negative aspects of caregiving.

The statistical analysis utilized data from 97 caregivers. I calculated frequencies and percentages for the demographic and contextual variables. To study the relationship between variables, I used Pearson's correlation. Stepwise multiple regression provided an analysis of the relationship among the main research variables and demographic and contextual variables that were correlated with objective and subjective burden. I identified themes from the qualitative data and calculated frequencies for each theme.

Significant Findings

The overall picture of family caregiving that emerged from the data was one of caregivers incurring high levels of objective burden related to confinement and infringements on their lifestyle, but relatively lower levels of subjective burden. This supported the findings of previous researchers (e.g., Thompson & Doll, 1983; Montgomery et al., 1985) who found the level of objective burden to be greater than the level of subjective burden. Montgomery et al. (1985) found that objective burden was related to informal support and caregiving tasks, whereas subjective burden was related to characteristics of the caregiver, specifically income and age of the caregiver. My findings indicated that the caregiver's health, the amount of assistance with caregiving tasks, and informal supports were significantly correlated with objective burden. In regression analysis, however, only health status of the caregiver was significant in explaining the variance of objective burden at $p < .05$. Although age and employment status of the caregiver was correlated with subjective burden, no demographic variables were significant in explaining the variance in subjective burden in stepwise regression analysis. This is contrary to the Montgomery and associates (1985) findings. One contextual variable, the presence of home health services, was significant in explaining the variance in subjective burden. Most previous studies have not found formal supports significantly related to burden.

The variable that was significant in explaining both objective and subjective burden was family strain. This is a new finding; previous investigators have not studied this variable in relation to caregiver burden. The weighted score provided an assessment of the pile up of potentially stressful events or changes that had occurred in the caregiving family during the last year. Although most of the reported events and changes were those one would expect in a family with a sick elderly member, the findings indicated that the effects of caregiving on other areas of the caregiver's life influenced the levels of objective burden and subjective burden.

The primary focus of this study was the coping patterns that caregivers used and the influence of these patterns on objective burden and subjective burden. The hypothesis was that if the primary caregiver is using patterns of coping responses that are conducive to positive well-being, the caregiver's subjective burden and objective burden will be low. The findings did not support this hypothesis. Even though the coping pattern that dealt with managing the medical situation was marginally correlated with objective burden (r=.18, p <.10) in stepwise regression analyses none of the coping patterns were significant in explaining the variance in objective burden or subjective burden.

The finding that none of the coping patterns were significant in accounting for the variance in either type of caregiver burden differs from the findings of Pratt et al. (1985) that four types of copings strategies were significantly correlated with caregiver burden. The correlations in that study were also relatively low (r=.16 to r=.26). It is possible that regression analysis of the Pratt group's data would also result in the coping patterns being nonsignificant if the model included other independent variables with higher zero-order correlations.

My study extended Pratt et al.'s (1985) research in two ways. First, recognizing that caregiver burden is a multidimensional construct, I examined subjective and objective components of burden separately. Pratt et al. used the Caregiver Burden Scale by Zarit et al. (1981) that combines the dimensions of objective and subjective burden into one burden score. Second, I sought to explain the variance in each type of burden by conducting multiple regression analyses. In this type of analysis one can examine the association among variables in relation to the influence of other independent variables. Also, one can assess the relative importance of independent variables in explaining the variance in the dependent variable.

By way of review, in Chapter 1 (Figure 1), I conceptualized the research variables as being related in a cyclical fashion with characteristics of the caregiver and carereceiver determining the attempts that caregivers made to provide assistance. The provision of care affects other areas of the caregiving family's life, leading to pile up of strains that members must deal with. They choose coping responses in an attempt to contend with the feelings of stress that multiple strains produce. Over time, the tendency to select certain coping responses to deal with similar problem areas leads to the establishment of coping patterns. The effectiveness of the coping pattern in dealing with the stress incurred as the result of the multiple strains influences the caregiver's level of objective and subjective burden. The level of burden, in turn, influences the caregiver's ability and attempts to provide further care.

Perhaps timing of the data collection is responsible for the the lack of relationship between the coping patterns and subjective and objective burden. Medicare reimburses the cost of skilled nursing care only until the client's health situation has stabilized. In this study, the median months that clients had been receiving home health services was 2 months although the mean was 7 months. It is possible that we were trying to assess coping patterns in situations in which not enough time had elapsed for the caregiver to establish coping patterns that would reduce caregiver burden.

There may also be an efficacy factor related to coping patterns and perceptions of objective and subjective burden. It is possible that caregivers' subjective burden was low because they have been using coping responses that were so effective in reducing their burden that they were not cognitively aware of feelings that would translate into a high subjective burden score. It is also possible that the coping responses used by caregivers to deal with their objective burden were not as effective in reducing feelings of burden, thus leading to higher objective burden scores. Because of having feelings and perceptions that translate into high objective burden scores, they are more aware of strategies that address these feelings and preceptions and, therefore, evaluate these responses as helpful. The fact that the coping pattern for managing the medical situation was marginally correlated with objective burden indicates that this may be the pattern of coping that caregivers are most aware of using to deal with their problems. Perhaps the variables in the model need to be rearranged so that the level of subjective and objective burden determines the types of coping responses chosen. Through repeated cycles of choosing certain coping responses to deal with high levels of subjective and objective burden, families may become more aware of coping patterns than they seemed to be in this study.

Religious beliefs may have influenced how families perceive the burden of caregiving and how they cope. Church teachings about the importance of family members and how persons should treat each other may help families to define the caregiving situation positively. This study did not elicit information about religious affiliation or beliefs but future research in this area would be helpful.

Cultural influences also may have been responsible for the caregivers' relatively lower level of subjective burden and the type of coping responses reported as either helpful or not helpful. Strong (1984) found that the cultural background influenced how Indian caregivers and white caregivers interpreted stressful situations. Indians used passive forbearance more often than whites to deal with stressful situations where they had little control. Perhaps cultural expectations of persons in this area of Southwest Virginia are that families should care for elderly relatives at home and not feel burdened. These expectations may also include not holding the elderly person responsible for his or her actions. Thus, the caregiver must not admit feelings that the caregiver is manipulative or shows lack of appreciation. The study did not include questions about the cultural background or beliefs of caregivers, therefore, one can only spectulate. This is an area for future research.

Another possible explanation for the lack of support for the hypothesis is that categorizing the coping responses according to McCubbin et al.'s (1981) factor analysis results may not be appropriate for assessing the coping patterns of caregivers for elderly family members. For example, scores from items that describe passive coping responses are included with active coping responses to assess the coping dimension maintaining family relations, integration, cooperation, and an optimistic definition of the situation. Perhaps categorizing responses according to whether they involve passive or active coping responses or dividing the responses into more than three patterns would help to show significance in the relationship and indicate the differential importance of various coping patterns. With a larger sample size, one could use factor analysis to re-examine the dimensions that McCubbin and associates (1981) identified. In future research, this type of analysis should precede analysis of relationships between coping patterns and other variables. Researchers should also examine other tools for their applicability in assessing caregiver coping. For example, Pratt and associates (1985) used the Family Crisis Oriented Personal Evaluation Scale (FCOPES) developed by

McCubbin et al. (1981) and reported the need to include other internal and external coping strategies in future research, suggesting that the range of coping strategies included in the tool is not comprehensive.

Implications and Recommendations

Theoretical Implications

The findings indicate the importance of including the pile up of family strain in the study of caregiver burden. They support McCubbin and Patterson's (1983) Double ABCX Model of adjustment and adaptation in which the family is conceptualized as a system with all members being influenced by change. However, the findings do not support the idea that coping is the bridging concept wherein resources, perception, and behavioral responses interact. Scholars should conduct more research, however, before drawing conclusions. As stated earlier, possible problems with the measurement of coping dimensions and the timing of data collection in relation to the caregiving cycle may have influenced the results. Longitudinal research in which the investigators could collect data at frequent intervals (such as biweekly or monthly) should be helpful in establishing whether coping patterns determine adaptation or whether adaptation determines the coping responses chosen and patterns established. Such studies may be able to identify the build up of various family strains, the timing of implementation of coping behaviors, and the evolution of coping strategies. The findings would also help to determine the appropriateness of the Double ABCX Model for studying caregiver burden.

The findings indicate that adaptation may not be dichotomous or either bonadaptive or maladaptive. Rather it may vary in different areas of personal and family life. The hypothesis was that if family members chose coping responses that were bonadaptive, both objective and subjective burden would be low. Results showed that different variables influenced each area and caregivers showed differing levels of adaptation with respect to each. Therefore, the caregiver may be bonadaptive in one area and maladaptive in another. This has implications for using the Double ABCX Model to study caregiver burden and other family problems. Perhaps researchers should consider the possibility of expanding the model to include the potential of both outcomes being associated with a given family situation.

Other results that have theoretical implications include the findings about the positive and negative aspects of caregiving. The number of caregivers who mentioned both positive and negative effects was greater than that reported in any other study. Perhaps it is the anticipation of positive rewards that influences the caregiver's decision to attempt to provide care. The balance of positive and negative rewards may determine why caregivers continue to provide care despite high levels of burden, especially objective burden. Investigators could use exchange theory to study this balance of costs and rewards for caregivers. They could use the themes identified from the responses to open-ended questions to develop items to quantitatively assess the balance of postive and negative aspects in caregiving.

Practical Implications

The findings about the importance of the pile up of family strains have implications for the way home health agencies deliver their services to families. Traditionally, nursing assessments and interventions have focused predominantly on the identified client and, specifically, on the health problems and status of the client. When I examined records at home health agencies to obtain demographic data about the carereceiver, I found few written remarks about the problems the caregiver and the caregiving family were experiencing. Yet nurses often commented that one of their biggest problems was being able to provide care for the client and also meet the caregiver's need to talk about feelings and concerns within the time constraints of the home visit. This research indicates the importance of considering the pile up of family strain and its influence on the caregiver's objective and subjective burden. It is possible that a high level of family strain which results in high caregiver burden, especially subjective burden, is related to an increased incidence of neglect and abuse. Therefore, home health personnel can identify caregivers in families with a pile up of potentially stressful changes and events as being at high risk for experiencing high levels of objective and subjective burden. Developing a family focus rather that a client focus in home care could mean that more elderly persons can receive care that is satisfying for the carereceiver, the caregiver, and the caregiving family.

This study supported the findings of other researchers that the biggest problems for caregivers are confinement and infringement on their lifestyle. Governmental and local agencies should address the need for relief and respite for caregivers when informal supports are not available. Most caregivers for elderly are near retirement or retired and living on fixed incomes. When caregivers do not know if funds are adequate to cover the present and future financial needs, they are usually hesitant to use these funds to hire a sitter just to get away or have time to themselves. Even in families were funds allow this, they often cannot find someone to provide this service. In addition, many caregivers are leary of employing someone without references or personal recommendations. Yet, to continue providing home care that is beneficial for the carereceiver and at least not detrimental for the caregiver, periodic relief from caregiving tasks and responsibilities is important. Because health of the caregiver was related to objective burden, perhaps agencies could use certification by a physician that the caregiver has health problems that require respite from homecare tasks as part of the criteria for determining who is eligible for restricted respite services.

The number of home health agencies increased dramatically when third party payment (mainly Medicare) began reimbursing the cost of skilled nursing and other related home health services. If funds were available to reimburse costs for adult day care and in-home respite care for families unable to pay, agencies would soon be established to address this need. Researchers should study the degree of respite care that caregivers need to reduce their sense of objective burden. Perhaps brief periods of respite, so that the caregiver can attend church, go to lunch with a friend or family member, or play a game of bridge, are all they would need to reduce feelings of burden. During interviews with caregivers, several indicated this need for brief respite and for flexibility in scheduling it at times other than the usual business hours.

Although no particular coping dimension was significant in explaining the variance in caregiver burden, there were definite trends concerning strategies that staff members need to be aware of. First, strategies that assist the caregiver in defining the situation as one of optimisim are important. However, caregivers were realistic and did not feel that it was helpful to believe the carereceiver would get better (if this was not a reasonable expectation considering the carereceiver's condition). Their belief in God was very helpful in dealing with the problems of caregiving and maintaining optimism about the situation. Staff members should be aware of this in counseling caregivers about the carereceiver's status. Allowing caregivers who are religious to verbalize how caregiving relates to their religious beliefs could be helpful.

The caregiver's assessment that everything possible was being done for the carereceiver, that the family was performing care tasks properly, and that all professional personnel had the family's best interest in mind were very important in coping with caregiving. This has implications for formal support workers and especially for the administrators of agencies who must hire staff members. It is extremely important that staff members be perceptive of the entire family situation and how caregiving tasks can fit into the family's lifestyle. If multiple service agencies are involved with a family, they must coordinate well so that the caregiver is not confronted with conflicting information or recommendations. Staff members should perform caregiving tasks promptly and proficiently. Caregivers indicated that being able to talk with health professionals was very helpful in coping with their situation. Therefore, agencies should plan staff members' schedules with time allotted so that there are opportunities for caregivers to ask questions and discuss concerns.

The findings about the positive and negative aspects of caregiving also have implications for health professionals. Staff members can assist family members in verbalizing their feelings and perceptions about the positive rewards they receive from caregiving rather than only inquiring about problems and negative effects. They can also encourage family members to verbalize these feelings to each other. From the comments of many caregivers in this study, taking care of an elderly family member can be a rewarding experience. Investigators in future research should focus on interventions that are effective in maintaining a balance in the costs and rewards of caregiving.

A few of the caregivers mentioned the need for more information about caring for an elderly person who is sick. During interviews, several caregivers stated that they do not use the coping strategies related to reading more about the medical problem and how people in similar situations manage because this type of reading material is not available to them. One caregiver wrote, "I would like to see places like your own department doing more to help people such as myself, e.g. more public education on our problems and promote things like day care facility for adults." A caregiver whose mother-in-law had terminal cancer stated that it would be so helpful to have information about what to expect during the course of disease, especially assistance with understanding the carereceiver's behavior. This indicates a need for a method to exchange information between formal support systems and caregivers. For example, an agency or extension service could be established where caregivers could call for specific information about their situation. Periodically, this agency could publish a newsletter to provide information that affects many caregivers. The newsletter could also provide an opportunity for caregivers to exchange ideas about how they manage certain problems or situations, what caregiving means to them, and how they feel on issues such as Medicare regulations, adult day care, and so forth.

The last implication of these findings for future practice deals with the need to assess the difference having formal support services makes in coping patterns and the level of subjective and objective burden. As stated earlier, although the caregivers in families receiving home health services and those who were not receiving services had similar mean levels of objective burden, the caregivers who were not receiving home health assistance had significantly higher mean levels of subjective burden even though the degree of assistance that their relatives needed was usually less than that required by home health clients. Investigators need to compare groups not receiving a particular service with those who are in order to establish the importance of formal support.

In conclusion, the importance of the pile up of family strains in explaining both subjective and objective burden indicates the need to utilize a systems perspective when studying or assisting family caregivers responsible for a sick or disabled elderly family member. Future researchers should continue to explore the role of coping in adapting and adjusting to the caregiver role. As a society, we must address ways in which we can assist caregivers in meeting their own needs as they provide care for their relatives. This study also identified that caregiving involves a balance of rewards and costs for the caregiver. This exchange warrants further exploration.

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APPENDIX A

Questionnaire and Correspondence

FAMILY CAREGIVING: A STUDY OF HOW FAMILY MEMBERS FEEL AND COPE

Family Caregiving Project
Janet M. Alley, Director
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FAMILY CAREGIVING QUESTIONNAIRE

Part A. Caring for a sick family member can be both good and bad. Below are some of the changes and problems other caregivers have.

Which of the following has changed for <u>you</u> since you began caring for your family member? CIRCLE the number that best describes your situation.

		A LOT MORE				A LOT LESS
1.	Amount of time you have to yourself.............	5	4	3	2	1
2.	Amount of privacy you have......................	5	4	3	2	1
3.	Amount of money you have to meet expenses.......	5	4	3	2	1
4.	Amount of personal freedom you have.............	5	4	3	2	1
5.	Amount of energy you have.......................	5	4	3	2	1
6.	Amount of time you spend in social and/or recreational activities.........................	5	4	3	2	1
7.	Amount of vacations and/or trips you take.......	5	4	3	2	1
		WORSE				BETTER
8.	Your relationships with other family members....................................	5	4	3	2	1
9.	Your health.....................................	5	4	3	2	1

Part B. Listed below are some of the feelings that other caregivers have.

How often do you have each feeling? CIRCLE the number which best describes you.

	MOST OF THE TIME OR ALWAYS				RARELY OR NEVER
1. I feel that it is painful to watch my relative age	5	4	3	2	1
2. I feel useful in my relationship with my relative	5	4	3	2	1
3. I feel afraid for what the future holds for my relative	5	4	3	2	1
4. I feel strained in my relationship with my relative	5	4	3	2	1
5. I feel that I am contributing to the well-being of my relative	5	4	3	2	1
6. I feel that my relative tries to manipulate or control me	5	4	3	2	1
7. I feel pleased with my relationship with my relative	5	4	3	2	1
8. I feel that my relative doesn't appreciate what I do for him/her as I would like	5	4	3	2	1
9. I feel nervous and depressed about my relationship with my relative	5	4	3	2	1
10. I feel that my relative makes requests that are over and above what she/he needs	5	4	3	2	1
11. I feel that I don't do as much for my relative as I could or should	5	4	3	2	1
12. I feel that my relative seems to expect me to take care of her/him as if I were the only one she/he can depend on	5	4	3	2	1
13. I feel guilty over my relationship with my relative	5	4	3	2	1

Part C. "Coping" means the way you manage hardships or problems. How do you cope when you have problems or feel upset about caring for your sick family member?

Please read <u>each</u> coping behavior and circle HOW HELPFUL it has been for <u>you</u>. If you do not cope that way, circle 0 for NOT USED.

	HELPFUL IN COPING				
<u>Family Relations and Beliefs</u>:	VERY HELPFUL			NOT HELPFUL	NOT USED
1. Trying to keep our family life stable or normal.	4	3	2	1	0
2. Trusting my husband/wife (or former spouse) to help support me	4	3	2	1	0
3. Showing that I am strong	4	3	2	1	0
4. Getting other members of the family to help with chores and tasks at home	4	3	2	1	0
5. Believing that my relative will get better	4	3	2	1	0
6. Believing that all health workers who deal with my relative have my family's best interest in mind	4	3	2	1	0
7. Believing in God	4	3	2	1	0
8. Believing that my relative is getting the best medical care possible	4	3	2	1	0
9. Going out with my spouse on a regular basis	4	3	2	1	0
10. Doings things with my children	4	3	2	1	0
11. Doing things with family relatives (other than spouse and children)	4	3	2	1	0
12. Telling myself that I have many things to be thankful for	4	3	2	1	0
13. Encouraging my relative to be more independent	4	3	2	1	0
14. Building a closer relationship with my spouse	4	3	2	1	0
15. Devoting myself to my relative	4	3	2	1	0
16. Talking about my feelings and concerns with my spouse	4	3	2	1	0
17. Believing that things will always work out	4	3	2	1	0

	HELPFUL IN COPING				
	VERY HELPFUL		NOT HELPFUL		NOT USED
Activities and Feelings:					
1. Being with people who make me feel important and appreciated	4	3	2	1	0
2. Working at a job outside the home	4	3	2	1	0
3. Working hard at my job	4	3	2	1	0
4. Buying gifts for myself and or other family members	4	3	2	1	0
5. Sleeping	4	3	2	1	0
6. Eating	4	3	2	1	0
7. Getting away by myself	4	3	2	1	0
8. Building close relationships with people	4	3	2	1	0
9. Developing myself as a person	4	3	2	1	0
10. Keeping myself in shape and well groomed	4	3	2	1	0
12. Having friends visit in our home	4	3	2	1	0
13. Becoming more self reliant and independent	4	3	2	1	0
14. Spending time on hobbies (art, music, sewing, woodworking, etc.)	4	3	2	1	0
15. Doing things with friends	4	3	2	1	0
16. Allowing myself to get angry	4	3	2	1	0
17. Talking to someone (other than a professional counselor or doctor) about how I feel	4	3	2	1	0
18. Getting away from home care tasks and responsibilities for some relief	4	3	2	1	0
Dealing With the Medical Situation:					
1. Talking with the doctor about my concerns about my relative	4	3	2	1	0
2. Talking with other medical people such as the home health nurse or aide	4	3	2	1	0

HELPFUL IN COPING

	VERY HELPFUL			NOT HELPFUL	NOT USED
3. Having my sick relative seen by a doctor on a regular basis..................................	4	3	2	1	0
4. Taking good care of all the medical equipment at home..	4	3	2	1	0
5. Being sure medical treatments are carried out correctly......................................	4	3	2	1	0
6. Talking with other people in the same type of situation and learning about their experiences...	4	3	2	1	0
7. Reading about how other people in my situation handle things..................................	4	3	2	1	0
8. Telling friends and neighbors about our family situation so they will understand us.............	4	3	2	1	0
9. Reading more about the medical problems which concern me......................................	4	3	2	1	0

Part D. Most families who are caring for a sick member also have other things happening. Which of the following events or changes have happened in your family during the last year?

"Family" means two or more people who are related by blood, marriage, or adoption. It includes people living with you and others not living with you who are important to you, such as your children and grandchildren.

Please read each family life change below and check whether it happened to you or your family during the LAST 12 MONTHS. Check YES or NO for each change. If a situation does not apply to you (e.g., you are not married or have no children) check N.A. for NOT APPLICABLE.

Changes for Family Members: CHANGED IN LAST 12 MONTHS

1. A member had emotional problems.................. ___YES ___NO ___N.A.

2. Increase in conflict between husband and wife..... ___YES ___NO ___N.A.

3. Increase in arguments between parent(s) and children.. ___YES ___NO ___N.A.

4. Increase in conflict among children in the family. ___YES ___NO ___N.A.

5. Increased difficulty in managing child(ren)....... ___YES ___NO ___N.A.

6. Increase in the number of problems which don't get solved... ___YES ___NO ___N.A.

CHANGED IN LAST 12 MONTHS

7. Increase in the number of tasks or chores which don't get done.................................. ___YES ___NO ___N.A.

Changes Between Husbands and Wives:

1. You or one of your parents was separated or divorced.. ___YES ___NO ___N.A.

2. You, your husband/wife, or one of your parents had an "affair"................................... ___YES ___NO ___N.A.

3. Increased problems in dealing with a "former" or separated husband/wife......................... ___YES ___NO ___N.A.

4. Family member had unwanted or difficult pregnancy. ___YES ___NO ___N.A.

5. A member gave birth to or adopted a child......... ___YES ___NO ___N.A.

Money and Work Changes:

1. Change in conditions (economic, political, weather) which hurt the family business.......... ___YES ___NO ___N.A.

2. Change in Agriculture Market, Stock Market, or Land Values which hurt family investments and/or income.................................. ___YES ___NO ___N.A.

3. A member started a new business.................. ___YES ___NO ___N.A.

4. Increased strain on family money for medical/dental expenses................................. ___YES ___NO ___N.A.

5. Increased strain on family money for food, clothing, energy, home care...................... ___YES ___NO ___N.A.

6. Increased strain on family money for child(ren)'s education........................... ___YES ___NO ___N.A.

7. A member started or returned to work.............. ___YES ___NO ___N.A.

8. A member stopped working for an extended period (laid off, leave of absence, strike, retirement).. ___YES ___NO ___N.A.

9. A member became less satisfied with job/career.... ___YES ___NO ___N.A.

Illness and Family Care Changes:

1. Parent or husband/wife became seriously ill or injured .... ___YES ___NO ___N.A.

2. Child became seriously ill or injured............. ___YES ___NO ___N.A.

3. A member became physically disabled or chronically ill... ___YES ___NO ___N.A.

CHANGED IN LAST 12 MONTHS

4. Increased problems with managing a chronically ill or disabled member.............................. ___YES ___NO ___N.A.

5. Increased responsibility to give care or financial help to your husband/wife's parent(s)............ ___YES ___NO ___N.A.

6. A member or close relative was admitted to an institution or nursing home...................... ___YES ___NO ___N.A.

Losses:

1. Your parent or husband/wife died................. ___YES ___NO ___N.A.

2. A child member died.............................. ___YES ___NO ___N.A.

3. Death of your spouse's parent or close relative... ___YES ___NO ___N.A.

4. Close friend of the family died.................. ___YES ___NO ___N.A.

5. Married son or daughter was separated or divorced. ___YES ___NO ___N.A.

6. A member "broke up" a relationship with a close friend... ___YES ___NO ___N.A.

Transitions "In and Out" of the Family:

1. A member was married............................. ___YES ___NO ___N.A.

2. Young adult member left home..................... ___YES ___NO ___N.A.

3. A young adult member began college (or training program)... ___YES ___NO ___N.A.

4. A member moved back home or a new person moved into your home... ___YES ___NO ___N.A.

5 . You or your spouse started school (or training program) after being away from school for a long time.. ___YES ___NO ___N.A.

Legal Violations:

1. A member went to jail or juvenile detention....... ___YES ___NO ___N.A.

2. A member was picked up by police or arrested...... ___YES ___NO ___N.A.

3. Physical or sexual abuse or violence in the home.. ___YES ___NO ___N.A.

4. A member ran away from home...................... ___YES ___NO ___N.A.

Part E. Next are some questions about you and your family. Remember that all information will be kept confidential.

Information about you, the primary caregiver:

1. What is your sex? (CIRCLE the number)
   1 FEMALE
   2 MALE

2. What is your race? (CIRCLE the number)
   1. Black
   2. White
   3. Other

3. How old were you on your last birthday? _________YEARS

4. What is your present marital status? (CIRCLE the number)

   1 MARRIED
   2 WIDOWED
   3 DIVORCED
   4 SEPARATED
   5 NEVER MARRIED

5. How many years of schooling did you complete? _____YEARS

6. Are you employed? (CIRCLE the number)
   1 NO
   2 YES

   If YES, About how many hours per week?____________ HOURS
   What type of work do you do?______________________________

7. How was your health for the past six months? (CIRCLE the number)

   1 VERY GOOD
   2 GOOD
   3 POOR
   4 VERY POOR

Information about your family:

1. How are you related to your sick family member? (CIRCLE the number)

   THE RELATIVE IS YOUR:
   1 WIFE
   2 HUSBAND
   3 MOTHER
   4 MOTHER-IN-LAW
   5 FATHER
   6 FATHER-IN-LAW
   7 SISTER OR BROTHER
   8 GRANDPARENT
   9 OTHER (Please specify _____________________)

2. What was your family income for the last year? (CIRCLE the number)

	YEARLY	<u>OR</u>		MONTHLY
1	LESS THAN $5,000		1	LESS THAN $416
2	$5,001 TO 15,000		2	$417 TO 1,249
3	$15,001 TO 25,000		3	$1,250 TO 2,082
4	$25,001 TO 35,000		4	$2,083 TO 2,916
5	$35,001 TO 45,000		5	$2,917 TO 3,750
6	$45,001 TO 55,000		6	$3,751 TO 4,583
7	OVER $55,001		7	OVER $4,584

3. How much help does your sick family member need with these tasks? (CIRCLE the AMOUNT OF HELP you give for EACH task.)

		NO HELP					TOTAL HELP
1	FEEDING	0	1	2	3	4	5
2	TOILETING	0	1	2	3	4	5
3	NURSING CARE	0	1	2	3	4	5
4	BATHING	0	1	2	3	4	5
5	DRESSING	0	1	2	3	4	5
6	BED TRANSFER	0	1	2	3	4	5
7	WHEELCHAIR TRANSFER	0	1	2	3	4	5
8	TELEPHONE	0	1	2	3	4	5
9	MONEY MANAGEMENT	0	1	2	3	4	5
10	PERSONAL AFFAIRS	0	1	2	3	4	5
11	MEDICATIONS	0	1	2	3	4	5
12	LAUNDRY	0	1	2	3	4	5
13	MEAL PREPARATION	0	1	2	3	4	5
14	HOUSEWORK	0	1	2	3	4	5
15	YARD CARE	0	1	2	3	4	5
16	WALKING	0	1	2	3	4	5
17	TRANSPORTATION	0	1	2	3	4	5
18	ERRANDS	0	1	2	3	4	5
19	OTHER--Please explain ____________________	0	1	2	3	4	5

4. How much does each person help you in caring for your relative? (CIRCLE your answer for EACH. If you don't have the person described, CIRCLE 6.)

		NO HELP					A LOT OF HELP	DON'T HAVE
1	YOUR HUSBAND/WIFE............	0	1	2	3	4	5	6
2	YOUR CHILD(REN)..............	0	1	2	3	4	5	6
3	ONE OF YOUR SISTERS/BROTHERS..	0	1	2	3	4	5	6
4	SEVERAL OF YOUR SISTERS/ BROTHERS......................	0	1	2	3	4	5	6
5	YOUR RELATIVE'S HUSBAND/WIFE..	0	1	2	3	4	5	6
6	YOUR RELATIVE'S SISTER/ BROTHER......................	0	1	2	3	4	5	6
7	NEIGHBORS, FRIENDS, CHURCH MEMBERS, ETC...........	0	1	2	3	4	5	6

5. Which professionals or service agencies provide services to your family member? (CIRCLE an answer for EACH.)

		YES	NO
1	FAMILY PHYSICIAN..............	1	2
2	MEDICAL SPECIALIST(S) (e.g. cardiologist)..........	1	2
3	HOME HEALTH AGENCY...........	1	2
4	PRIVATE SITTER................	1	2
5	HOSPICE......................	1	2
6	HEALTH DEPARTMENT............	1	2
7	SOCIAL SERVICES DEPARTMENT....	1	2
8	HOSPITAL.....................	1	2
9	RESPITE CARE..................	1	2
10	OTHER--Please explain____________________________		

6. Are there any agencies or professionals you are not using now but would use if available? (You may use the above list or add others.)

7. Where does your family member live in relation to you? (CIRCLE number and letter)

1 RELATIVE LIVES IN THE SAME HOME WITH YOU

Whose home? (CIRCLE the letter)
A IN RELATIVE'S HOME
B IN YOUR HOME
C OTHER (Please explain ______________________________.)

<u>OR</u>

2 RELATIVE LIVES IN SEPARATE HOME FROM YOU

How far away? (CIRCLE the letter)
A IN YOUR NEIGHBORHOOD
B IN YOUR TOWN/COUNTY
C OUTSIDE YOUR TOWN/COUNTY

8. What positive or good things have happened for you and/or your family because of caring for your family member?

9. What negative or bad things have happened for you and/or your family because of caring for your family member?

Is there anything else that you would like to tell us about caring for your family member? If so, please write it below.

Thank you for your help with this study. If you would like a copy of the results, print your name and address on the back of the return envelope--not on this questionnaire. Return the questionnaire in the enclosed envelope.

DEMOGRAPHIC DATA ABOUT THE CARERECEIVER

1. I.D. Number ________

2. Your relative's sex? ______FEMALE (1) ______MALE (2)

3. Your relative's race? ______BLACK (1) ______WHITE (2) ______OTHER (9)

4. Your relative's birthdate ________________ age? ______YEARS

5. Relative's main health problem (refer to list below)________________
____

6. Relative's other diagnosed health problems.

01. HEART CONDITION
02. CIRCULATION PROBLEMS
03. HIGH BLOOD PRESSURE
04. ANEMIA
05. DIABETES
06. RESPIRATORY PROBLEMS
07. CATARACTS
08. STOMACH ULCERS
09. BROKEN BONE
10. GALL BLADDER PROBLEMS
11. HERNIA
12. LIVER DISEASE
13. KIDNEY DISEASE
14. URINARY PROBLEMS
15. PARKINSON'S DISEASE
16. STROKE/CVA
17. ALZHEIMER'S DISEASE
18. ARTHRITIS
19. SKIN PROBLEMS
20. CANCER
21. EMOTIONAL PROBLEMS
22. MEMORY PROBLEMS
23. THYROID PROBLEMS
24. EPILEPSY/SEIZURES
25. OTHER ______________________________

7. Functional Limitations

01. AMPUTATION
02. BOWEL/BLADDER (incontinence)
03. CONTRACTURE
04. HEARING
05. PARALYSIS/PARESIS
06. ENDURANCE
07. AMBULATION
08. MENTAL
09. SPEECH
10. VISION
11. RESPIRATORY
12. DEPENDENT FOR ALL ACTIVITIES
13. OTHER ______________________________

8. Mental Status

1. ORIENTED 2. FORGETFUL 3. DISORIENTED 4. AGITATED
5. COMATOSE 6. DEPRESSED 7. LETHARGIC 8. OTHER

9. Location.

1 URBAN
2 SUBURBAN
3 RURAL

VIRGINIA TECH

Department of Family and Child Development
College of Human Resources

Wallace Annex
Blacksburg, Virginia 24061-8299
(703) 961-4794 or 4795

Family Caregiving Project

Dear Caregiver:

I am a doctoral student in Family Studies at V.P.I. & S.U. and a nurse who teaches nursing at Radford University. During the next three months, I will be conducting a study of how family members, like you, manage the care of older relatives in the home. There is little information on how caregivers feel about their situation and how they cope with their problems. The answers you and others in the study give will be helpful to other caregivers and to health workers.

As a member of the study, you will answer questions which will take about one-half hour of your time. I will mail the questionnaire to you and you can mail it back at no expense, or, I will be happy to come and fill out the questionnaire for you. Your name will not appear on the questionnaire, and all information will be kept confidential. If you are willing to be in the study, please sign the consent form giving your home health agency permission to give me this information. The consent of your relative is also needed so that information such as age and medical diagnosis can be obtained from the chart. Again, all information will be kept confidential.

If you have questions or need to know more about the study, call me at (703) 951-7912 or leave a message for me at your home health agency. Thank you for your assistance.

Sincerely,

Janet M. Alley

Virginia Polytechnic Institute and State University

FAMILY CAREGIVER CONSENT FORM

I, ____________________, am willing to participate in the Family
(Print)
Caregiving Research Project being sponsored by the Department of Family and Child Development at V.P.I. & S.U., and conducted by Janet Alley, Project Director.

______ The questionnaire may be mailed to my address at:

____

____________________________________(Zip Code)

______ I will need help completing the questionnaire. Call me at ______________ to set up an appointment.

Signed: ____________________________
Caregiver

I, ____________________, do hereby give my consent to and authorize
(Print)
______________________________ to release unto Janet Alley, Project Director for the Family Caregiving Project being sponsored by V.P.I. & S.U., medical information contained in the medical record compiled while I have received home health care. I understand that this information is to be used for the purpose of providing information for the research study and that purpose only. I understand that this consent is subject to revocation by me at any time, and unless an earlier date is specified, that it automatically expires ninety (90) days after the date affixed below.

__________________________ DATE	Signed______________________________ Patient; (guardian if mentally incompetent)
__________________________ Print Patient's Name	______________________________ Relationship If Signed by Other Than Patient
__________________________ Patient's Age/Date of Birth	______________________________ Witness (Name & Position)

VIRGINIA TECH

Department of Family and Child Development
College of Human Resources

Wallace Annex
Blacksburg, Virginia 24061-8299
(703) 961-4794 or 4795

Family Caregiving Project

Dear Caregiver:

Caring for a family member who is sick or disabled can bring both rewards and problems. But there is little information available about the benefits of caregiving or how caregivers cope with problems. We are conducting a study of how people like you feel about the care they give and the problems they face.

Recently, you agreed to be a part of the Family Caregiving Project being sponsored by the Department of Family and Child Development at V.P.I. & S.U. You can give information which no one else can provide. In order for the results to really describe how caregivers feel, each questionnaire must be completed by the family member who does the day-to-day care for a sick or impaired person age 60 or older. All information will be kept confidential. The booklet has an identification number for mailing purposes only. Your name will never be connected with your answers in any way.

I would be happy to answer any questions you have about this study. Feel free to write or call. My telephone number is (703) 951-7912. Your home health agency is assisting with our study and you may leave a message for me there. Please return your questionnaire this week by mailing it in the enclosed envelope. Thank you for your assistance.

Sincerely,

Janet M. Alley, Director
Family Caregiving Project

Virginia Polytechnic Institute and State University

VIRGINIA TECH

Department of Family and Child Development
College of Human Resources

Wallace Annex
Blacksburg, Virginia 24061-8299
(703) 961-4794 or 4795

Family Caregiving Project

Dear Caregiver:

Recently we mailed a questionnaire on family caregiving to you. If you have completed and returned this questionnaire, please accept my sincere thanks. If not, your prompt response will be very much appreciated. It is important that your questionnaire be included in the study if the results are to be truly representative. If by chance you did not receive the questionnaire or cannot complete it, please call me at (703) 951-7912 or your home health agency.

Thank you for your assistance.

Sincerely,

Janet M. Alley, Director
Family Caregiving Project

Virginia Polytechnic Institute and State University

APPENDIX B

Certification of Exemption of Projects Involving Human Subjects

CERTIFICATION OF EXEMPTION OF PROJECTS
INVOLVING HUMAN SUBJECTS

Principal Investigator(s) Janet McDaniel Alley

Department(s) Family and Child Development

Project Title Family Caregiving

Source of Support: Departmental Research __ Sponsored Research __ Proposal No. ______

1. The criteria for "exemption" from review by the IRB for a project involving the use of human subjects and with no risk to the subject is listed below. Please initial all applicable conditions and provide the substantiating statement of protocol.

☐ a. The research will be conducted in established or commonly established educational settings, involving normal education practices. For example:
   - a) Research on regular and special education instructional strategies;
   - b) Research on effectiveness of instructional techniques, curricula or classroom management techniques.

☐ b. The research involves use of education tests (☐ cognitive, ☐ diagnostic, ☐ aptitude, ☐ achievement), and the subject cannot be identified directly or through identifiers with the information.

☑ c. The research involves survey or interview procedures, in which:
   - ☐ a) Subjects cannot be identified directly or through identifiers with the information;
   - ☑ b) Subject's responses, if known, will not place the subject at risk of criminal or civil liability or be damaging to the subject's financial standing or employability;
   - ☑ c) The research does not deal with sensitive aspects of subject's own behavior (illegal conduct, drug use, sexual behavior or alcohol use);
   - ☐ d) The research involves survey or interview procedures with elected or appointed public officials, or candidates for public office.

☐ d. The research involves the observation of public behavior, in which:
   - ☐ a) The subjects cannot be identified directly or through identifiers;
   - ☐ b) The observations recorded about an individual could not put the subject at risk of criminal or civil liability or be damaging to the subject's financial standing or employability;
   - ☐ c) The research does not deal with sensitive aspects of the subject's behavior (illegal conduct, drug use, sexual behavior or use of alcohol).

☑ e. The research involves collection or study of existing data, documents, records, pathological specimens or diagnostic specimens, or which:
   - ☐ a) The sources are publicly available; or
   - ☑ b) The information is recorded such that the subject cannot be identified directly or indirectly through identifiers.

2. I further certify that the project will not be changed to increase the risk or exceed th exempt condition(s) without filing an additional certification or application for approv by the Human Subjects Review Board.

Note: If children are in any way at risk while this project is underway, the chairman of the IRB should be notified immediately in order to take corrective action.

12/11/87

Signature: Principal Investigator(s) Date Signature: Principal Investigator(s) Date

12.15.87

(Optional Approval) Signature: Board Chairman/Authorized Reviewer Date

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