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The effects of social factors on adult children caring for older parents

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University of Washington, 1991

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The Effects of Social Factors on Adult Children Caring for Older Parents

by

William J. Strawbridge

A dissertation submitted in partial fulfillment
of the requirements for the degree of

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to Offer Degree Department of Sociology

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Abstract

The Effects of Social Factors On Adult Children Caring for Older Parents

by William J. Strawbridge

Chairperson of the Supervisory Committee: Professor Edgar Borgatta
Department of Sociology

This study was designed to test a model of the effects of selected social factors and caregiving tasks on caregiving outcomes for 100 adult children caring for frail, elderly parents or in-laws. Results are analyzed using path analysis. Social factors included relationship quality, duty, caregiver support upset, and caregiving satisfaction. Caregiving outcomes included caregiver perceived burden, caregiver mental health, and likelihood of nursing home placement. Care-receiver dementia and caregiver income were added during model testing.

Both caregiver perceived burden and care-receiver dementia increased likelihood of nursing home placement while duty decreased it. Relationship quality, caregiver support upset, and caregiving tasks indirectly affected likelihood of nursing home placement through their effects on caregiver perceived burden. Relationship quality reduced perceived burden, while caregiver support upset and caregiving tasks increased it. Relationship quality also indirectly reduced the likelihood of nursing home placement by increasing duty. Higher income reduced perceived burden by decreasing caregiving tasks. Caregiver mental health, as measured by the Mental Health Inventory, had no

effect on likelihood of nursing home placement when caregiver perceived burden was taken into account.

Caregiving satisfaction was shown to be redundant and was dropped from the model. Relationship quality appeared to measure the same underlying construct and had stronger associations with the other variables.

That caring for a parent can be burdensome is evidenced by the relatively low scores on the Mental Health Inventory and by the strong association between caregiver perceived burden and mental health.

Subjects were also asked whether they were having problems with relatives over caregiving. Forty percent reported experiencing conflict or resentment toward another family member; in the majority of the cases (65%) the relative was a brother or sister. The most frequently reported source of the problem was lack of sufficient caregiving assistance. Caregivers reporting conflict or resentment evidenced significantly poorer mental health, poorer relationship quality with their care-receivers, higher perceived burden, and were more likely to be considering nursing home placement for their care-receivers than were those not reporting conflict even when controlling for caregiving tasks. Those having conflict with relatives were also much more likely to prefer alternatives to family care for themselves should they become disabled.

This study shows that, with the exception of duty, social factors in caregiving impact likelihood of nursing home placement through their effects on caregiver perceived burden. Family conflict also appears to have an important impact on caregiving outcomes.

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I would also like to acknowledge the help of a number of individuals who not only went out of their way to provide assistance but also helped me gain a greater appreciation and understanding of my research field and professional direction.

The caregivers who were interviewed for this study or who took part in the pretest often had to juggle difficult schedules and time commitments to share their experiences; some made valuable suggestions to improve the study. Several helped recruit other subjects. Most went beyond merely answering the questions and expressed their ideas with great poignancy and self-evaluation. Without their assistance this dissertation would be still just an interesting idea on a computer disk.

Margaret Wallhagen provided many of the ideas behind this research, secured two of the sites, suggested several analysis strategies, edited the final report, and was encouraging when things seemed to be falling apart.

Gerrie LaQuey, DeLila Thorp, Mary Lou Chalberg, Nora Stabler, Dorothea

Hayes, Doris Weaver, and Mariann DiMinno from six of the recruiting sites compiled potential subject lists and handled mailings when their only reason for cooperating was that they believed in the importance of research and the implications for improving caregiving services. Doris Weaver also recommended an analysis strategy that did not work but was intriguing none-the-less. Linda Crossman from Marin Adult Day Health Services agreed to take part in the study as a recruitment site and got out a critical mailing to potential subjects all in only three days near the end of the study when time was very short. Maura Egen recommended the Senior Resource Center for a site, from which ultimately one-third of the subjects came. Marianne Davis from the Senior Resource Center was particularly helpful, supporting looking at family conflict as a variable and responding to my many requests for "just one more mailing" with patience and good humor.

Bill Erdly suggested using the caregiver support upset scale; the results indicate his wise counsel. Margaret Rothman suggested using the Mental Health Inventory, a measure that facilitated mental health comparisons with non-caregivers. Susan Hedrick recommended using the full social support scale (which facilitated making the upset/helpful comparisons), recommended using the VA two-step format for scale responses, and responded promptly to numerous drafts with thoughtful comments. Ed Wallhagen suggested adding an item dealing with worry to the caregiver perceived burden scale. Jean Sullivan gave extensive assistance in designing and pretesting the questionnaire. She also taught me how to conduct a good interview and recommended the assistant interviewer used on the study. Laura Hebert went beyond the call of duty in interviewing; she took the study seriously and made strenuous efforts to interview hard-to-schedule caregivers. Her car died in the line of duty, but her enthusiasm never wavered. Edgar Borgatta helped secure funding from the Veterans Administration, recommended using the four-point response set for the scales, and kept me on schedule. Mary Walsh helped me through the complex VA requirements and procured extensive administrative support. Victor Bovbjerg provided extensive help with computer programming. Herbert Costner advised me in writing the hypotheses, the use of path analysis, and in interpreting the results. Jim McCann talked me out of using stepwise regression, a technique that could have yielded misleading results. Ed Perrin inspired me to go back to graduate school and finish the PhD I started years ago, while Joan Abe in the Graduate School helped me deal with paperwork and meeting the requirements. Fred Campbell welcomed me back to Sociology after such a long absence and argued for the importance of making long-term care policy recommendations based upon the results from this study. Michelle Marshall and Lloyd David shared their home with me during data collection and analysis in Seattle. Katherine Rickey served as an inspiration to become involved in issues affecting older persons, while Debby Peterman encouraged my shift from acute care service planning to long-term care.

I am greatly indebted to all the persons above. Scholarly research is indeed a team effort.

CHAPTER I

INTRODUCTION

In 1900 there were just over 3 million Americans 65 years old and older and they made up only 4% of the total population. By 1960 their numbers had grown to 16 1/2 million, and they now made up 9% of the total population. In 1980 that number had increased to over 25 million and was projected to exceed 31 million by 1990 (U.S. Bureau of the Census, 1984). More than 12% of the American population is 65 years old or older.

This extremely rapid growth in the number of persons 65 years old and older has been accompanied by an increasing demand for health care services. Elderly persons are major consumers of health care in the United States, accounting for 20% of physician visits, 41% of the hospital days, 90% of nursing home days, and 33% of total health care costs (U. S. Senate Special Committee on Aging, 1987-88).

These changing demographic patterns present American society with a problem not previously experienced -- how to care for large numbers of dependent elderly persons. As Hareven (1977) points out, previous generations experienced high mortality, high fertility, and economic precariousness. Three generation families were not common. A large number of dependent elderly persons is a new phenomenon.

Persons 65 years old and older are not a homogeneous group, however. The diversity within this population has important health and social implications. Those elders 85 years old and older constitute a segment that has the greatest percentage growth rate and by far the highest nursing home use rate among those 65 and older. About 22% of persons 85 and over are residents of nursing homes compared with only 1% of those 65-74 (Hing, 1987). The relatively rapid growth of the 85 plus segment has been an important factor in the recent sharp increase in nursing home utilization, which has more than doubled since just 1966 (U. S. Senate Special Committee on Aging, 1987-88).

In spite of the much higher rates of health care service utilization, it is important to remember that America's elderly generally live by themselves. Only 5% live in nursing homes (U.S. Senate Special Committee on Aging, 1987-88) and only 12% reside with relatives (Moroney, 1980); less than 20% of those with living children reside with them (Shanas, 1979). Separate residences for American elderly stand in sharp contrast to some other societies, where multigenerational living patterns are the norm. In Japan, for instance, 80% of the elderly live with their relatives, usually their children (Plath, 1983). Separate living patterns and the high value American culture places on independence make for ambivalence on the part of both the elderly and their children when increasing frailty mandates the need for care. As will be seen, the great majority of care to the frail elderly is provided by other family members, but such informal care may be disruptive to both those receiving and giving the care.

Family Caregiving: Who Receives It and Who Provides It

While the vast majority of the elderly live alone and require little assistance, one-fourth of those 65 and older who live in the community are estimated to need help on at least one Activity of Daily Living (ADL) and/or one Instrumental Activity of Daily Living (Dawson, Hendershot, and Fulton, 1987). ADLs include very basic physical activities, such as bathing, eating, dressing, toileting, walking, and getting in and out of bed and chairs. Sometimes incontinence is also included as a separate item. IADLs include more secondary functions, such as preparing meals, shopping, taking medications, handling money, and doing housework.

The bulk of assistance on ADLs and IADLs is not provided by paid helpers but by other family members. The Informal Caregivers Survey (Stone, Cafferata, and Sangl, 1987) estimated that from 1.6 to 1.8 million of the two million elderly persons identified in 1982 as having ADL limitations were assisted in their dependencies by one or more unpaid caregivers. That such a high proportion of the disabled elderly rely on informal caregivers for care points to the importance of such caregivers not only in providing care but also in keeping such persons out of nursing homes. Absence of family care is one of the main reasons why frail persons are admitted to nursing homes in the first place (Kane and Kane, 1987); were it not for support from others, many more elderly persons would reside in some kind of institutional care.

Because care-receivers often had more than one caregiver, the person most likely to be a caregiver in the Informal Caregivers Survey was an adult child. However, a different picture emerges when only primary caregivers (those most responsible for care of a particular person) are considered; then the most likely caregiver is a spouse. Stone, Cafferata, and Sangl suggested that a hierarchy of caregiving exists, with spouses being the primary caregivers if they are available, and children normally assisting. Fitting conventional wisdom, adult daughters were twice as likely as adult sons to be primary caregivers.

Caregiving is a time-consuming activity. In the Stone, Cafferata, and Sangl study, primary caregivers reported spending an average of four hours a day, seven days a week in caregiving; 80% of them lived with the care-receiver. Mean age was about 70 for spouses, 50 for adult children.

Policies Surrounding Family Care of the Frail Elderly

The importance of family care for elderly persons with chronic health problems has become an important aspect of public policy as health care costs, the number of elderly persons, and the proportion of the elderly being care for in nursing homes have all steadily increased. Nursing home care presently costs about $25,000 per year for each patient (Liu and Manton, 1989). Nursing home expenditures for the entire country approached $40 billion in 1986, up from just $2 billion in 1965 (Otten, 1988; Freeland and Schendler, 1981). The impact on both state and federal budgets of such an increase has been great, since these two sources make up about half of all nursing home expenditures. Given such high costs, it is not surprising that substituting lower cost alternatives would have a high priority.

It must be acknowledged that payments to nursing homes are by no means the major component of health care expenditures for the elderly -- hospitals receive far more, while physician services cost about the same as nursing home care (Waldo and Lazenby, 1984). But nursing home care is of such concern because government payments for it are nearly all through the Medicaid program (which comes out of general state and federal revenues), rather than the Medicare trust fund (which is paid for by employers and recipients). Thus each year increasing Medicaid expenditures for the elderly must compete with all of the other governmental programs that are funded from general revenues.

From a payor's standpoint, the cheapest alternative to nursing home or other institutional care is family care. Not only is family labor "free" as far as the payor is concerned, but families are already providing the majority of the care to elderly persons with chronic health problems. Extending such care appears as a logical extension of what is already being done by choice, so the obvious course for cost-conscious legislatures is to find ways to extend family care and discourage nursing home admissions.

While seeming to be sensible from an economic standpoint, increasing the emphasis on family care follows a long period during which institutionalization was seen by many professionals as the preferred treatment mode for both physical and mental illness. During much of both the nineteenth and twentieth centuries family environments were seen both as potential causes of disabilities (mental illness) or poor treatment environments (physical and mental illness), with the result that institutional treatment was to be preferred (Rothman, 1971). Unlike in the eighteenth century, family life was not viewed as benign, but rather as a source of demands to which individuals had to either "adapt, accommodate, or escape" (Heller, Swindle, and Dusenbury, 1986: 446). Escape was either toward an institution or toward independence from the family setting. Poor family life was often singled out as a primary cause of problem behavior, much as it still is today for poor and minority youths. Even as recently as 20 years ago the Group for the Advancement of Psychiatry (1970) reported that the primary goal of 87% of family therapists was to improve the autonomy and individual development of family members. Family care was not necessarily seen as beneficial.

The current shift in emphasis to family care thus represents a major change from the view that family life and community settings were partly responsible for stress and illness to the view that they are nurturing settings for the prevention and treatment of illness. Such a change has not come about solely because of concerns about cost. It is also consistent with a growing emphasis on individual rights, a general ethos of deinstitutionalization, and the realization that institutionalization, with its attendant loss of rights, was imposed less on adult males than on females and others with fewer resources. There is strong evidence that quality of care in many nursing homes is poor (Institute of Medicine, 1986; Vladeck, 1980). Generally speaking, for both patients and their relatives, entering a nursing home occurs only with great reluctance and after other means of care have been exhausted (Brody, 1977). It is seen as a treatment of last resort.

While there is evidence that relatives view placement of a disabled family member as the least desired form of treatment and prefer family care if possible, the current policy shift from emphasizing institutional care to emphasizing family care has been made in the absence of objective data that care by relatives is necessarily to be preferred. As far as health and functional ability of the care-receiver is concerned, several studies have indicated that there is little difference between a variety of care options, including good nursing home care (Sherwood, Morris, and Ruchlin, 1986; Weissert, 1985). While simply looking at daily costs will clearly favor alternatives to institutionalization, many family caregiving situations are not beneficial for either or both of the parties involved. Elder abuse has been a popular media concern recently, and some abusive situations involve care-receivers as victims. In a survey of adult child caregivers, Steinmetz (1988) reported that 23% of them said they had struck or thrown things at the parent they were caring for. While stopping short of actual physical abuse, other home settings may fail to provide the quality of care or physical and social stimulation that might be present in a good institutional setting.

Of equal concern should be abuse of caregivers. Caregiving responsibilities fall primarily on women, raising questions about fairness in a society with a stated policy of promoting equal employment and other rights for women (Briar and Ryan, 1986). Some care-receivers tyrannize their caregivers with incessant demands and verbal abuse (Lezak, 1979), while others may have been abusive parents or spouses in the past. In the Steinmetz study, 18% of the caregivers she interviewed reported that their elderly parent had struck or thrown things at them while they were providing care. Caring for an aging parent may also reopen old wounds or cause resentment because of feelings on the part of the caregiver that the parent was not a good father or mother. Caregivers may feel strong family pressure to care for someone that they would just as soon see institutionalized, yet feel helpless to resist such pressures because of a sense of family obligation.

There is some evidence that institutional care may actually improve family relationships. Smith and Bengtson (1979) followed 100 nursing home patients and their families for two years after institutionalization and found that the majority reported improved relationships with family members. The researchers attributed the improvement to better physical care, freeing of relatives from the physical aspects of care (thereby allowing them to concentrate on the more enjoyable aspects of their relationships with their parents), and better opportunities for socialization that were present in the nursing home.

What does seem clear is that total health care costs cannot be reduced by increasing supportive services to home caregivers in the hopes of delaying institutionalization. Such supportive services as home-health, adult day health care, support groups for caregivers and respite care can certainly enhance the care being provided in home settings, although one odd finding from the demonstration projects is that many caregivers offered alternative services make no use of them (Montgomery, 1988). Those that do use the services likely use them more because they provide add-on services to care already being provided than because they substitute for institutionalization of the care-receiver (Weissert, 1985). None of the randomized trials of family caregiving alternatives to nursing home placement reviewed by Weissert showed reduced long-term care costs as a result of the alternative programs offered. Caregivers who desire supportive services but will continue caring without them simply constitute a larger group than those who will institutionalize the person they are caring for unless they receive such services. Offering more supportive services may improve the quality of care provided at home, but it will not reduce overall health care costs.

Importance of Social Factors for Caregiving

Social factors have figured prominently in caregiving studies and have been shown to affect caregiving outcomes. Several studies have shown that the available resources and the caregiving setting (which include social factors) have more effect on caregiver well-being than do the disabilities presented by the care-receiver (George and Gwyther, 1986; Zarit, Reever, and Bach-Peterson, 1980).

Certain factors that impact caregiving have already been studied extensively. Studies have focused on caregiver characteristics, variations in type of burdens experienced, changes over time, types of caregiving tasks performed, variations in caregiving by different disease categories, and the effects of social support. Several potentially important social factors, however, have received little attention. Sense of duty for caring and relationship quality have been included in only a few studies, yet they are the two most common reasons given for providing care (Horowitz and Shindelman, 1983) and may have very different consequences for the experience of caregiving (Brickman, 1987). Caregiving satisfactions have recently been recognized but have not been studied systematically as an independent variable. Social support has been widely studied, but nearly always in terms of the numbers of helpers or the caregiver satisfaction with it . Few studies have looked at the potentially negative aspects of supportive services, such as measuring the caregiver's level of disgruntlement with the help received. No single study has examined the combined effects of relationship quality, duty, caregiving satisfaction, and a negative measure of social support to determine how these variables might operate together to affect caregiving outcomes.

Understanding how all of these social factors affect caregiving outcomes and impact service preferences is important for future service development. Caregivers themselves may also benefit from understanding the various motivational factors inherent in caregiving and the problems attending assistance (or lack thereof) from others. Support services may be quite appropriate in one situation, while institutional care may be better in another even when the health problems of the care-receiver are the same. If factors such as relationship quality, duty, satisfactions, and network upset do impact caregiving, it may be possible to better tailor services to individual situations.

CHAPTER II

CONCEPTUAL FRAMEWORK

Conceptual Framework and Major Specific Measures

This study was designed to broaden the understanding of caregiving provided by adult children for their elderly parents by investigating the relationships of four social factors that have been shown individually to affect caregiving outcomes but have not been examined together. These four social factors are relationship quality, duty, social support upset, and caregiving satisfaction. The relationships among these variables were explored along with their influence on two caregiving outcomes (perceived caregiving burden and caregiver well-being). Furthermore, the influences of perceived caregiving burden and caregiver well-being on the on the caregiver's perceived likelihood of placing the care-receiver will be placed in a nursing home were also explored. Extent of caregiving tasks performed by the caregiver was included because prior research showed it to be an important factor affecting perceived caregiving burden.

Each of the eight variables included in this study are now examined in turn. A model of the proposed variables and hypothesized relationships is presented in Figure 1.

Relationship Quality

An affectionate relationship with a frail parent may not be a necessary condition for caregiving. While Brody (1985) states that affection and emotional

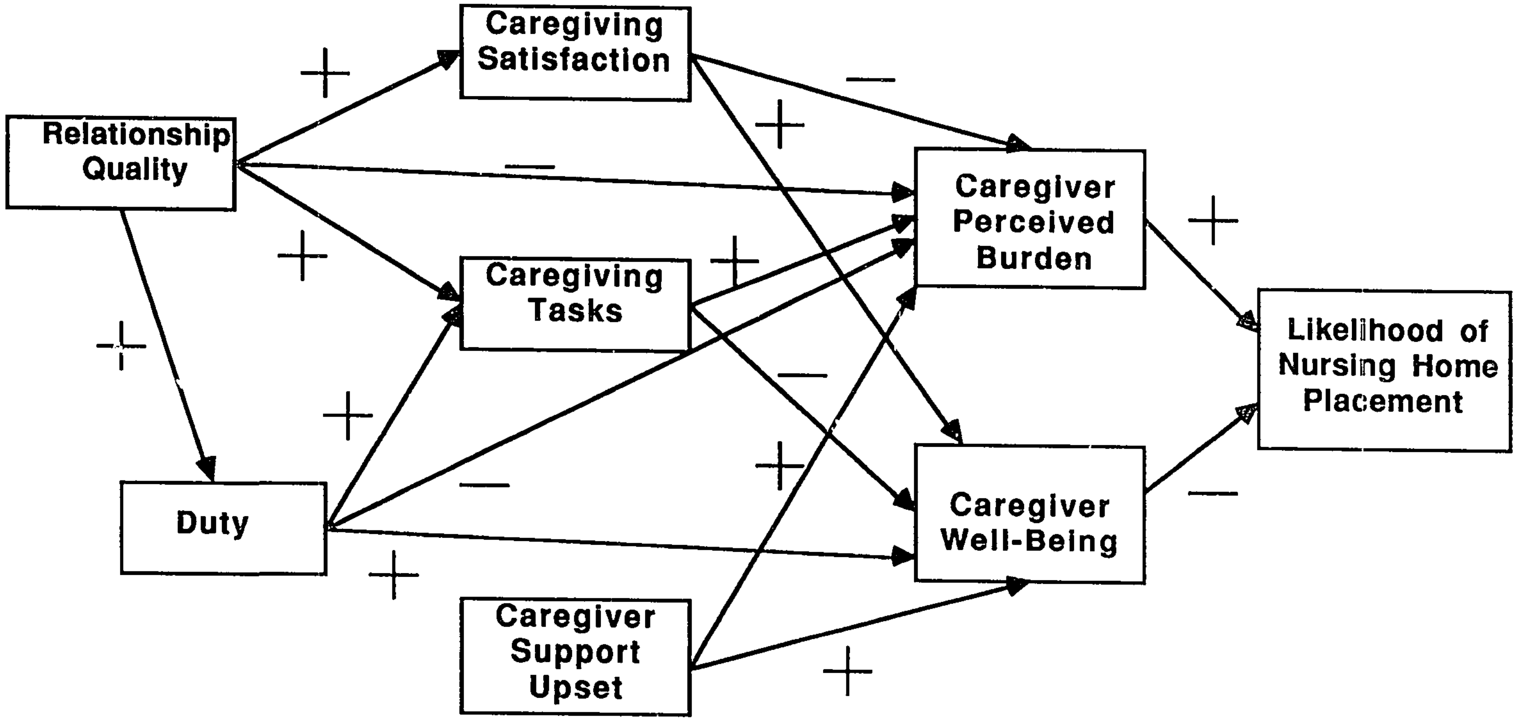


Figure 1. Original Path Model with Hypothesized Relationships

support for a frail parent are filial norms, Jarrett (1985) disagrees and places caregiving into the more general set of mutual obligations that bind families together. Just because parents and children are usually emotionally close does not mean that such closeness continues into the adulthood of the child. Family members do have certain obligations to assist one another, Jarrett argues, but it is not necessary for them to like one another.

While affection may not be a necessary aspect of caregiving according to Jarrett, it is often mentioned by caregivers as an important reason for what they do. When asked why they provide care to parents, adult children generally rank relationship quality with the parent quite high. In one study relationship quality (measured by feelings of love and affection) ranked first (Walker, Pratt, Shin, and Jones, 1988), while Horowitz and Shindelman (1983) reported that relationship quality (as measured by present affection and reciprocity for past actions) was only exceeded by family obligation as a reason for providing care. In spite of its apparent importance, however, relationship quality has rarely been included in caregiving studies as an independent variable to determine its relationship with caregiving outcomes.

One of the studies that did examine relationship quality as an independent variable involved caregiving spouses rather than adult children. Fengler and Goodrich (1979) reported that present relationship quality (as measured by whether the caregiver felt her care-receiving husband was a confidant) was positively correlated with life satisfaction scores for caregiving wives. For caregiving adult children, Cantor (1983) used compatibility as a measure of relationship quality and found a weak positive relationship between compatibility and caregiver strain; however, extent of caregiving tasks was not controlled for, so it is impossible to know whether such surprising results might have been due to more tasks being performed by caregivers who felt they were compatible with their care-receivers. Scharlach (1987) studied 40 mother-daughter pairs and reported a negative relationship between present quality and caregiver role overload (extent to which the daughters felt they were being asked to do too much).

Two studies have attempted to measure changes in relationship quality over time as a result of caregiving. Both have design problems. In a study that examined only 11 caregivers of care-receivers with Alzheimer's disease, Blieszner and Shifflett (1990) showed that intimacy between them and their care-receivers declined during an 18 month period. Walker, et al. (1990) approached change over time on a cross-sectional basis, asking 133 adult daughter caregivers whether their relationships with their mothers had improved, gotten worse, or stayed the same as a result of caregiving. Half said it had improved, 44% said it had stayed the same, and only 5% reported that it had gotten worse. There was a possible selection bias in favor of those who got along well, however, since subjects had been told that the study involved relationships with their mothers and were required to secure the cooperation of the mother before the interviews took place. Care-receivers with mental impairments were also excluded from the study. Given the limitations of these two studies, it is difficult to make a conclusion about changes in relationship quality over time.

Given the importance of relationship quality as a rationale for providing care, it was included in this study as an independent variable. Both present and past aspects of the relationship were included in constructing the measurement scale, which allowed for a rough comparison of change over time. Cross-sectional approaches to change are always suspect, of course, because subjects may have a tendency to change their views of the past as a result of present events. Because of the importance ascribed by caregivers to relationship quality as a motive for caring, relationship quality was hypothesized to vary negatively with perceived caregiving burden and to vary positively with caregiver well-being.

Three indirect links to perceived caregiving burden and well-being were also hypothesized. First, relationship quality was hypothesized to have an indirect effect on perceived caregiving burden and well-being by having a direct, positive relationship with caregiving tasks. In other words, caregivers who have a better sense of relationship quality with their care-receivers tend to take on more caregiving tasks. The second indirect relationship involves a direct relationship with duty. Based upon the Horowitz and Shindelman study just described, the Finley, Roberts, and Banahan study to be described shortly, and upon statements from caregivers (such as "How could I not take care of my dad now when he did so much for me when I was a child?"), relationship quality was also hypothesized to have an indirect effect on the two caregiving outcome variables by having a direct, positive relationship with duty. Finally, as will be discussed later, relationship quality was hypothesized to have a further indirect effect on the dependent variables by varying positively with caregiving satisfaction.

If the hypothesized relationships for relationship quality hold, this variable will be in the interesting position of affecting caregiving outcomes in opposite ways: directly it will reduce burden and increase well-being. Indirectly, one relationship (increasing caregiving satisfaction) will increase the direct effects while the other two proposed indirect links (increasing caregiving tasks and increasing sense of duty) will have partially offsetting effects. The variable's net effect will then depend upon the relative strengths of these four paths, but such complexity may explain why researchers examining only several of these variables at a time have reported inconsistent results for the relationships between relationship quality and caregiving outcomes.

Duty

Duty is defined as caring for a parent or in-law out of a sense of family obligation. Historically it is not clear that adult children have such a duty to care for their elderly parents or in-laws when they become disabled or frail. In their study of the Middle Ages, Gies and Gies (1987) found a lack of consensus as to the obligation of children in such circumstances as did Wrigley (1977) in examining family obligations in Elizabethan England. In the United States, Hareven (1977) argues that high mortality and fertility rates coupled with economic uncertainty made for few stable three generation families until the present time.

Regardless of history, a very large percentage of American adult children say that older persons should be able to rely on their children for assistance when needed (Brody, 1981), and caring for a parent out of a sense of family obligation was mentioned as the primary reason for providing care in a survey of adult child caregivers (Horowitz and Shindelman, 1983). Yet the same adult children do not agree that they should have to adjust work schedules to care for their parents or live in the same house with a parent in order to provide care (Brody, Johnsen, and Fulcomer, 1984). Furthermore, caregivers and care-receivers may have different views of the extent to which duty serves as a motivation for care. In one study of mother-daughter pairs, less than one-third of the care-receiving mothers felt that their daughters were providing care out of a sense of obligation, while over 69% of the daughters reported some degree of obligation in caring for their mothers (Walker, Pratt, Shin, and Jones, 1988).

There thus appears to be ambivalence surrounding the duty of an adult child to care for a frail parent. General statements in support of a caregiving obligation become tempered by the specifics of the actual physical and social setting in which the caregiving will take place.

Few caregiving studies have attempted to link duty with other variables or measure it directly as a sense of obligation to care for one's own parents instead of general feelings about the duty of adult children to care for parents ("I feel I should take care of my mother" vs. "I feel adult children should take care of their mothers"). Results are likely to be different when specific measures are used, because caregivers are then talking about their own reality as compared with espousing broader, normative statements.

Cantor (1983) used a general measure for duty and reported that it was positively related to caregiver strain, while Horowitz and Shindelman (1983) found a positive relationship between duty (measured specifically) and affection between the caregiver and the care-receiver. Finley, Roberts, and Banahan (1988) studied duty as a dependent variable and found that affection was the variable most consistently related to it in four combinations of adult children describing their specific filial obligations toward each parent. Cicirelli (1983) included duty (measured generally) as an independent variable and found only an indirect positive relationship between duty and negative feelings toward caregiving with duty being related to frequency of contact which was in turn directly (and positively) related to negative feelings. As with relationship quality, such inconsistencies may be the result of failing to take other variables into account during data analysis; only Cicirelli used a credible multivariate approach.

For this study specific measures of duty were used, while feelings of the general obligation of adult children to care for aging parents were collected through an open-ended question. Following Brickman's (1987) analysis that caregiving provided as a result of obligatory motives will be experienced negatively by caregivers, duty was hypothesized to vary positively with perceived caregiving burden and inversely with caregiver well-being. Duty was also hypothesized to have a positive effect on caregiving tasks (i.e., the stronger the sense of duty that is felt by a caregiver, the greater the number of caregiving tasks that are taken on.) Duty was thus hypothesized to increase burden in two ways: directly by increasing perceptions of burden and indirectly by increasing the number of tasks attempted.

Caregiver Support Upset

Social network upset is based upon several recent studies suggesting that dissatisfactions with one's social network have a stronger effect on caregiving outcomes than do the more traditional measures of satisfaction or the number and extent of others who are providing assistance. Building on the earlier work of Fiore, Becker, and Coppell (1983), Pagel, Erdly, and Becker (1987) indicated that upsetting aspects of caregivers' social networks were more strongly related to depression than were helpful aspects, while Melichar, Okun, and Hill (1988) indicated that negative social relationships are an important predictor of overall network satisfaction/dissatisfaction for older persons. These studies may help clarify what has been a mixed picture of the effects of more general social "support" measures in caregiving studies. In some studies support has been shown to have an effect, while in others it has not (Kaplan, Cassel, and Gore, 1977). Social support (measured subjectively) has been shown to be negatively related to caregiver burden or well-being for some caregivers but not for others (Quahagen and Quahagen, 1988) and at the start of caregiving but not two years later (Zarit, Todd, and Zarit, 1986).

Part of the problem for the mixed results may lie in early assumptions that assistance from other relatives and acquaintances was invariably positive. In fact, assistance may be given grudgingly, critically, with lots of advice, or in other ways that cause problems for the caregiver involved. Family members may fight with one another over how best to care for the care-receiver; assistance may be expected but not received. Such family conflict or resentment among adult child caregivers has been mentioned in passing in the literature (Abel, 1989; Frankfather, Smith, and Caro, 1981; Hausman, 1979) but rarely quantified. Archbold (1980) reported that 50% of the caregivers in her study felt resentment toward inequality of the workload among family members, but she only interviewed 6 subjects. Rabins, Mace, and Lucas (1982) reported that 56% of the adult child caregivers in their study of demented care-receivers were experiencing a problem with other family members who were not helping or who were critical of the care provided by the caregiver. However, none of these studies examined the relationship of such conflict or resentment to caregiving outcomes. Brody, Hoffman, Kleban, and Schoonover (1989) found only low levels of "intersibling hassles" in their caregiving study but did note an association between such hassles and perceived burden.

It is certainly possible that feeling upset about negative aspects of social support in caregiving may be more powerful in terms of caregiving outcomes than a positive one. For this study, social network upset (defined as the extent to which a caregiver feels that significant others in his/her caregiving network are upsetting) was hypothesized to vary positively with perceived caregiving burden and inversely with caregiver well-being.

Additional information about the nature of the problem involved, who the upsetting person was, and what the caregiver had tried to do about the problem were also collected to shed more light on the upset vs. helpfulness issue. Caregiving outcomes for those experiencing a serious problem with those members of the support system described as upsetting were compared with those not experiencing such problems.

Caregiving Satisfactions

Defined here as perceptions on the part of the caregiver that certain aspects of the caregiving provided are beneficial to the caregiver and his/her family, caregiving satisfaction has not been studied until recently. It seems clear that when asked caregivers will report that selected aspects of their caregiving experience have been positive. For example, even in a sample of caregivers experiencing high levels of burden, Chenoweth and Spencer (1986) reported that some felt caregiving had drawn their family closer together or that the experience had given them pride in their ability to meet new crises. Horowitz (1985), Kinney and Stephens (1988), Murphy (1990), and Reese, et al. (1983) all demonstrated that caregivers could identify positive elements in their caregiving experiences, such as an improved sense of self-worth or growing closer to the care-receiver.

While it may be that finding satisfactions in difficult circumstances is simply a form of rationalization with few meaningful consequences (akin to asking someone recovering from a serious accident if he or she learned anything from the experience), it could be that caregiving satisfaction is more than ornamentation and does modify caregiving outcomes. So far studies taking the latter approach have had mixed results. Miller (1988) reported that satisfaction and caregiver stress were positively correlated, but the measurement procedures she used are so questionable that they cast doubt on the validity of her results. Moss has reported the conflicting findings that satisfaction and caregiver perceived burden are either positively correlated (1988) or that they are not (Moss, Lawton, Dean, Goodmann and Schneider, 1987). All three of the studies just reported were done for other purposes than testing caregiver satisfaction, and the measures used appear to have been added hastily. A definitive test of this variable has yet to be done.

While it seems clear that satisfaction is a common experience in caregiving the relationship it may have to caregiving outcomes is not clear. Without examining the effects of caregiving satisfaction in the presence of other variables it is impossible to know if this variable has any independent contribution to make to caregiving outcomes or not.

For this study caregiving satisfaction was hypothesized to vary inversely with perceived caregiving burden and positively with caregiver well-being. Since it seems reasonable that satisfaction will occur more frequently when the relationship quality between the caregiver and the care-receiver is positive, relationship quality was hypothesized to have a positive relationship with caregiving satisfaction.

Caregiving Tasks

Even though it is not always included in other studies, a measure of the actual involvement of the caregiver in caregiving is an important factor to consider in any caregiving study. Involvement in caregiving varies greatly from caregiver to caregiver both in terms of number of tasks performed and time actually spent on them (Horowitz, 1985; Stone, Cafferata, and Sangl, 1987). This study will utilize a measure combining actual tasks performed with their frequency of performance in a typical caregiving week. Caregiver tasks are hypothesized to vary directly with perceived caregiving burden and inversely with caregiver well-being. As previously discussed, both relationship quality and duty were hypothesized to have a positive relationship with caregiving tasks.

Caregiver Perceived Burden

It is ironic that at a time when there is an increased emphasis on family care as an alternative to nursing home care, there is also an increasing recognition of the existence of widespread burdens for those caring for disabled elderly relatives. The current concept of caregiver burden grew out of previous studies on the effects of the deinstitutionalization of mentally ill patients in the 1950's and 1960's. Thompson and Doll (1982) summarized a number of studies that attempted to measure the impact upon families of having previously institutionalized relatives return home for care. These earlier studies reported that about half of the families surveyed reported varying levels of burden, but results varied widely. Some studies reported few burdens, while others found relatively high levels.

Burden studies for caregivers of persons with disabilities other than mental illness began somewhat later then the deinstitutionalization studies. Brody (1969), Seelbach (1978), Lezak (1979), and Robinson and Thurnher (1979) were among the first to argue that caregivers of older adults faced high levels of burden; within a few years the view grew rapidly that nearly all caregiving was burdensome. As a result of the emphasis on burdens, the principal dependent variables studied have been aspects of caregiver burden, such as stress, depression, illness, low life satisfaction, and perceived burden.

To better calculate relative burdens, George and Gwyther (1986) utilized a control group of non-caregivers in a study of 510 caregivers of Alzheimer's Disease patients. Their burden measures indicated that, while the caregivers appeared no different in terms of physical health, they did show significantly higher levels of stress and lower levels of life satisfaction. Particularly striking were the lower levels of visiting, time spent on hobbies, and time spent relaxing for the caregiving group. Amy Horowitz (1985) surveyed a large number of studies and concluded that emotional stress was the most difficult problem faced by caregivers, ranking ahead of physical demands, demands on time, and financial concerns. Horowitz also mentioned the problems of reduced labor force participation among caregivers and strains on caregiver family relationships.

Burden measures have also figured prominently in the work of many other researchers, especially those who have studied caregivers of demented or mentally ill care-receivers (Cantor, 1983; Thompson and Doll, 1982; Zarit and Zarit, 1983). Chenoweth and Spencer's group of caregivers dealing with relatives afflicted with Alzheimer's disease showed particularly high levels of burden (1986); a similar group of caregivers was also found to suffer higher rates of illness than a non-caregiving control group (Otten, 1989). Whittick (1988) has shown that adult females caring for a demented parent experience more emotional distress than do mothers caring for retarded children.

Subjective feelings were shown to be important in the earlier studies of burdens connected with caring for someone with mental illness, and the distinction between objective burden (what a caregiver is doing) and subjective burden (how the caregiver evaluates what he/she is doing) has been carried over into caregiving for the frail elderly. What is perceived as burdensome by one caregiver will not necessarily be seen as burdensome by another (Montgomery, Stoll, and Borgatta, 1985; Thompson and Doll, 1982; and Wallhagen, 1990). One caregiver may deeply resent having to cut down on work in order to care for someone, while another may feel that caregiving is preferable to the boring job he/she had before. As such this variable occupies an intermediate position between the social factors and caregiving tasks just discussed and the dependent variable of likelihood of nursing home placement. Perceived caregiving burden was hypothesized to have a direct, positive association with likelihood of nursing home placement. The more burdened a caregiver feels, the more likely is that caregiver to consider nursing home placement as a way to reduce the burden.

The most widely used perceived burden scale in caregiving studies is Zarit's Burden Interview (Zarit, Reever, and Bach-Peterson, 1980), which is curious since this instrument was found to be related to only one other variable (number of visits received from other relatives) when it was first used. One problem is that it is extremely broad, including such items as impact on caregiver activities, attitudes about aging, affective feelings about the care-receiver, desire for more money, and caregiver concerns about his/her own reactions when interacting with the care-receiver. While activities, emotions, and physical feelings have emerged as distinct factors in two recent caregiving studies (Moss, et al., 1987; Poulshock and Deimling, 1984), the breadth of the

Zarit measure makes it impossible to sort out direct and indirect paths among the variables included in the current study. and likelihood of nursing home placement. A more direct approach was used by designing a scale that utilized the three factors just discussed but emphasized perceived caregiver feelings about the changes in their lives that had occurred as a result of caregiving.

Caregiver Well-Being

Well-being involves the affective feelings of the caregiver around the time of the interview. As such it involves an assessment on the part of the caregiver as to how the positive and negative aspects of his/her life at present compare with one another. Andrews and Withey (1976) argue that there are three dimensions to well-being measures: positive and negative affect or feelings, life-satisfaction (a more judgmental assessment of one's entire life), and intensity of feeling. Affect was selected for this study because it appears to be the well-being dimension most closely related to a burden measure evaluating caregiver perceptions of current lifestyle changes. Measuring well-being also allowed the results to say something specific about the extent to which caregiving impacts mental health. A burden scale is helpful, but it allows no comparison with more general aspects of a caregiver's life. To the extent that well-being is affected by the four social factors just described, the hypothesized relationships should logically be the opposite of those predicted between the social factors and perceived caregiving burden .

Likelihood of Nursing Home Placement

A few caregiving studies have used actual nursing home placement as a dependent variable. Zarit, Todd, and Zarit (1986) showed that higher levels of caregiver perceived burden were positively associated with subsequent nursing home placement two years later. At least two studies have used anticipated nursing home placement. Pett, et al., (1988) used a one item measure for desire to institutionalize the care-receiver and showed that it was positively related to perceived burden. Whittick (1989) used factor analysis to develop a "pro-instutionalization aspects of caregiving" measure and found that it was positively associated with caregiver emotional distress.

Given the cross-sectional design of the current study, a scale measuring caregiver perceptions of the likelihood of nursing home placement was substituted for actual placement. The prevailing view in caregiving research is that nursing home placement occurs only as a last resort after a long search for alternatives. Some consider it the most difficult decision that a caregiver has to make. If so, consideration of such placement is an activity not taken lightly and caregivers scoring high on a perceived likelihood of nursing home placement scale should be more likely to actually institutionalize the care-receiver in the future than a caregiver who scores lower. If perceived caregiving burden really does increase the likelihood of nursing home placement, then the importance of the four social factors and caregiving tasks included in this study will be increased. Such factors would then become more important in anticipating the setting for future care.

Demographic and Caregiving Variables

The social factors, caregiving outcome variables, and caregiving tasks were examined in association with standard demographic and caregiving measures included in many other studies. Those that showed significant relationships with the major variables were added to the path model for testing.

Research Questions -- Hypotheses to be Tested

This study tested the following hypotheses:

1. Higher relationship quality is associated with lower caregiver perceived caregiving burden and higher caregiver well-being. Indirectly, higher relationship quality also lowers perceived caregiving burden and increases well-being by having a positive relationship with caregiving satisfaction. Relationship quality has a partially offsetting association with burden and well-being by having a positive relationship with caregiving tasks and sense of duty.
2. Higher caregiver sense of duty is associated with higher caregiver perceived caregiving burden and lower caregiver well-being. Indirectly, higher caregiver sense of duty also increases perceived caregiving burden and decreases well-being by having a positive relationship with caregiving tasks.
3. Higher caregiving satisfaction is associated with lower caregiver perceived caregiving burden and higher caregiver well-being.
4. Higher caregiving tasks are associated with higher caregiver perceived caregiving burden and lower caregiver well-being.
5. Higher social network upset is associated with higher caregiver perceived caregiving burden and lower caregiver well-being.
6. Higher perceived caregiving burden is associated with higher perceived likelihood of nursing home placement; higher caregiver well-being is associated with lower perceived likelihood of nursing home placement.

CHAPTER III

METHODS

Research Design

This study used a cross-sectional, correlational design with non-probability sampling. A total of 100 adult child caregivers caring for elderly parents or parents-in-law were recruited from a variety of organizational sites in two different states. Data collection was by an in-person interview with the caregiver usually conducted in the subject's home.

Subject Recruitment

Potential subjects were recruited from eight organizational sites in Northwest Washington State and the San Francisco Bay area in California. Part of the design was to include caregivers in both urban and rural areas, and sites were chosen accordingly. Table 1 lists the names and major service components of these sites. Subjects could be either males or females. Eligibility criteria included taking care of a parent or parent-in-law who was at least 55 years old and who was not permanently living in a nursing home. Subjects did not have to be the primary caregiver for the care-receiver but did have to be providing at least 4 hours of care per week and assisting the care-receiver on at least one ADL (activities of daily living) or two IADLs (instrumental activities of daily living.) These are modest criteria for entry; but given the nature of the sites, most of the caregivers actually were doing far more caregiving than the minimum criteria for entry. Site staff identified potential subjects and sent them a letter describing the study in very general terms and describing the criteria necessary for taking part. Those who were interested in

Table 1. Subject Recruitment Sites

SITE and LOCATION	MAJOR SERVICES OFFERED
Evergreen Resource Network Redmond, Washington	Information and referral, assessment, home health
Harbors Home Health Aberdeen and Raymond, Washington	Home health
Marin Adult Day Health Services San Anselmo, California	Adult day health care
Olympic Area Agency on Aging Aberdeen, Washington	Information and referral
Seattle Day Center for Adults Seattle, Washington	Adult day health care
Senior Resource Center Puyallup, Washington	Information and referral, assessment, home health, caregiver support groups
UCSF Memory Clinic San Francisco, California	Information and referral, assessment
Visiting Nurse of King County Seattle, Washington	Home health

Table 2. Subject Flow from Initial Contact to Interview

ACTIVITY	NUMBER
Sent Initial Letter from Site Staff	412*
Returned Card Expressing Interest	128
Screened for Eligibility	126
Determined to be Eligible	105
Interviewed	100

*Approximate

being interviewed were asked to return a card in a self-addressed envelope. These recruitment materials may be found in Appendix 1. Those returning cards were contacted by one of the two interviewers, screened for eligibility, and then scheduled for an in-person interview if eligible and still interested. Most interviews were conducted in subjects' homes at a time when the care-receiver was not present. Place of employment or local restaurants were used when home interviews were not convenient. The interviews lasted about one hour after the informed consent forms had been explained and signed. For items with specific response options (such as the scales), subjects were given large cards with these options written out to facilitate understanding.

Other family members were not encouraged to be present during the interviews since they could easily inhibit the responses to the social support questions and to several of the open-ended items. In the few cases when they were present the interviewers varied the order of the scales, using the sensitive questions when the other members were temporarily preoccupied. In only two interviews did other family members (a husband in one case and an older son in another) insist on remaining within earshot for the entire questionnaire; in these two instances the caregivers being interviewed did not appear inhibited by their presence.

Human Subjects Procedures

All subjects were given Veterans Administration Form 10-1086 to read and sign before the interview was conducted. Depending upon the area involved, subjects also read and signed the appropriate informed consent forms approved either by the University of Washington or by the University of California, San Francisco. See Appendix 1 for a sample informed consent form.

Response Rates

Response information is summarized in Table 2. Numbers are approximate for the first row of the table because site personnel handled the initial mailing, and Human Subjects procedures forbad study investigators from contacting potential subjects or even knowing their names until they had seen the initial letter and expressed interest. Overall about 31% of those sent the initial letter returned the response cards indicating an interest in the study. There was wide variation in response depending upon the site involved. At the Seattle Day Center for Adults 50% of those initially contacted responded, while at the UCSF Memory Loss Clinic only 20% did so. Part of the reason for the relatively low response rate at the UCSF site was that several other research projects were underway at the same time and site staff limited the mailing to persons who were not taking part in the other studies and who had contacted the site more than one year previously. Some of those not returning the cards no doubt ruled themselves out on the eligibility criteria, because site personnel had been encouraged to send initial letters to anyone they thought might possibly be eligible. In order to update its mailing list, one site asked persons no longer caring for the indicated care-receiver to return the cards and indicate the reason -- 20% of those sent the initial mailing did so, with responses equally divided between saying that the care-receiver had died or had been institutionalized. If this 20% figure is true for all sites, then about 40% of eligible caregivers sent the initial letter responded.

Of those returning the cards, 83% were eligible following screening. The two main reasons for not being eligible were insufficient number of hours of caregiving or having already institutionalized the care-receiver. A few indicated that they were caring for grandparents or in one case a retarded child. Some of these persons said they knew from the initial letter that they were not really eligible but had responded because they still thought they had interesting things to say about caregiving, wanted information about available services, or just wanted to learn the results of the study. One woman who had just institutionalized her mother wanted counselling to deal with her unsympathetic husband. Several others had probably not read the letter very clearly; one of them actually sent a check for Alzheimer's research with her response. The check was returned.

Only five subjects determined to be eligible following screening were unable to be interviewed. Two had actually been scheduled for an interview but declined when the interviewer arrived. One of these felt she was too depressed to be interviewed and declined to reschedule, while another mistook the interviewer for a social worker and declined when she was told that taking part would not actually help her obtain home services. The care-receivers of the other three potential subjects died before interviews could be scheduled.

The methods used to recruit subjects are clearly not those of a randomized sample. These subjects were caregivers who had either received services from or contacted one of the cooperating sites and who had then self-selected themselves to be in the study. However, the introductory letter was purposely vague, referring to the purpose of the study as learning about the stresses and strains of caregiver in order to improve services; potential subjects did not know any of the specific hypotheses, measures, or even the subject areas before the interviewer arrived at their doorstep. Several subjects said that they specifically wanted to be in the study because they had a story to tell about either how difficult caring for an elderly parent was or conversely how fulfilling it was. Most said that they simply wanted to help others learn more about caregiving so that better services could be designed or so that others could learn from their experiences. Whether such recruitment techniques result in non-representative samples of caregivers responding or not is simply not known. Similar techniques to those used here or "captive audience" techniques (where caregivers attending a single large service organization are recruited by staff) are used in virtually all caregiving studies where outcomes are collected. This study did have one advantage over most other caregiving studies in that it recruited subjects from two different states and included sites in both urban and rural areas. The results of the current study can certainly be compared with other caregiving studies in the literature but still may not be representative of all adult-child caregivers in general.

Study Instruments

The questionnaire used in the study may be found in Appendix 2. Table 3 summarizes the major variables used and their appropriate study instruments. Each will now be examined in turn.

Relationship Quality

Relationship quality was measured with the scale developed by Walker and Thompson (1983) for their study of exchange and affection between daughters and their mothers. One question was added to assess similarity of values and four questions were added to specifically address past relationship quality. The scale has a total of 22 items. Higher scores indicate higher levels of relationship quality as reported by the caregiver. Walker and Thompson report reliabilities of from .91 to .97 in their use of the scale. No men were included in the original Walker and Thompson study, but the scale appears to

Table 3. Major Variables and Measures Used In the Study

CONCEPT	MEASURE	SOURCE
Quality of relationship between caregiver and care-receiver	Relationship Quality	Adapted from Walker and Thompson, (1983) with 5 added items to measure shared values and past relationship quality
Obligatory motives for providing care	Duty	Adapted from Seelbach and Sauer, (1977) with 9 added items to broaden the scale
Caregiver upset with those in support network	Caregiver Support Upset	Adapted from McCallister and Fischer (1978) and Pagel, Erdly, and Becker (1987)
Satisfying aspects of caregiving	Caregiving Satisfactions	Designed for the current study
Amount of caregiving provided	Caregiving Tasks	Adapted from Stetz (1986) and Wallhagen (1988)
Perceived impact of caregiving on caregiver's life	Caregiver Perceived Burden	Adapted from Moss, et al. (1987), Poulshock and Deimling (1984), and Wallhagen (1988)
Caregiver well-being	Mental Health Inventory	Veit and Ware (1983)
Caregiver feelings about eventual nursing home placement	Likelihood of Nursing Home Placement	Designed for the current study

have no gender bias. A 4 point response set (strongly agree, moderately agree, moderately disagree, strongly disagree) was used.

Duty

Duty was measured with a 13 item scale. Four of the items were adapted from Seelbach and Sauer (1977); nine new items were added to measure obligatory feelings of caring for the care-receiver over a wider range of activities than included in the Seelbach and Sauer study. The particular wording of 11 items involved specific feelings about the person being cared for, such as "Because (care-receiver) is my (relationship), I feel I should take care of (him/her) now that (he/she) is old and frail." For comparison purposes two general questions on the importance of family values and feelings about adult children caring for frail parents were also included. Scoring was with a 4 point response set (strongly agree, moderately agree, moderately disagree, strongly disagree.)

Caregiving Satisfactions

Designed for the current study, the satisfactions scale includes several items suggested by Moss, et al. (1987), Zarit, Reever, and Bach-Peterson (1980), combined with others obtained through exploratory interviews with caregivers for a total of 15 items. The items are designed to capture more long-term satisfactions (such as "I feel useful because I know I am helping someone") than momentary uplifts like feeling good today because the care-receiver smiled. Scoring was with a 4 point response set (strongly agree, moderately agree, moderately disagree, strongly disagree.) Higher scores indicate a higher level of satisfaction with caregiving.

Caregiver Support Upset

This scale involved a combination of the work of McCallister and Fischer (1978) and Pagel, Erdly, and Becker (1987) The specific instrument in the latter study asks subjects to name everyone (up to 15 names) who is important to the caregiver, asks how long they have known each person named, and whether they have come into contact with that person in the last two weeks. Persons named and seen in the last two weeks are then included in the upset/helpfulness measures that follow. This naming procedure risks diluting the instrument's effectiveness by including persons who may have no impact on the caregiving at all. At the same time it excludes persons that the caregiver feels should be helping but who are not if such persons have not been seen in the last two weeks. To yield a more succinct list and include those not helping the caregiver, the procedures recommended by McCallister and Fischer for describing a social support network were used in the current study. Caregivers were asked to list those who were helping them care for the care-receiver, those whom they felt should have been involved in helping them care but were not, and anyone that they talked with about problems or concerns that they had in dealing with the care-receiver. Up to six names were carried over to the upset/helpfulness questions. For those few subjects who listed more than six names, the list was reduced by starting with anyone named in the not-helping but should category and then going to those who were helping until the sixth name was reached. Caregivers were then asked both how upsetting and how helpful the persons named were across five dimensions of social relationships. These dimensions were help with caregiving tasks, providing information, sharing activities, providing emotional support, and closeness. A 4 point response set was used ranging from "not helpful" to "very helpful" for the helpful component and from "not upsetting" to "very upsetting" for the upsetting component. Scoring follows the Pagel, Erdly, and Becker method: helpful and upset scores for each dimension are summed respectively and then divided by the number of persons named. According to Pagel, Erdly, and Becker, the upset results are more powerful predictors than are helpful measures. Higher scores indicate greater levels of upset or helpfulness depending upon which component is being measured.

Caregiving Tasks

Caregiving tasks were measured with the Stetz Inventory, Part I (Stetz, 1986) as modified by Wallhagen (1988). This scale includes 15 specific questions about caregiving activities, such as "I help (care-receiver) with eating his/her food." However, Stetz simply coded the responses "yes" or "no." To allow for a more varied response the recommendations of Wallhagen will be followed to change the yes/no answers to a six item frequency range ("never," "rarely," "several times a month," "every week," "several times a week," and "daily.") Higher scores indicate more extensive involvement with caregiving tasks.

Caregiver Perceived Burden

The caregiver perceived burden scale was designed to emphasize changes in the caregiver's life that had occurred as a result of caregiving. Such changes were hypothesized to have a more direct impact on considerations of nursing home placement than would more the more global concerns typically found in perceived burden measures. Caregivers know what their lives were like before caregiving began; to the extent that they feel the changes have been negative they should be more likely to consider nursing home placement than if they perceive such changes as neutral or positive. Activity changes (such as no longer having enough time for oneself) made up the bulk of the items in the scale; but emotional factors (such as "I now worry about him/her all the time") and physical changes ("I now feel tired all the time") were also included.

Consisting of 22 items, this scale contained items adapted from Moss, et al. (1987), Poulshock and Deimling (1984), and Wallhagen (1988). Since the measure was designed to reflect perceived burden, the scale used in conjunction with each item asked caregivers to rate how much of a problem or concern each item was for them rather than simply asking them how often a particular item occurred. Caregivers vary in whether a change is perceived as a negative change or not. If friends and relatives come over less than they used to, for example, some caregivers will see the change as a loss while others will not. Categories used are "not at all a problem or concern," "sometimes a problem or concern," "usually a problem or concern," "often a problem or concern," and "always a problem or concern." The term "concern" was added based upon a recommendation by Steinmetz (1988), who noted that some caregivers object to the term "problem" to describe caregiving activities. Higher scores indicate higher levels of perceived burden.

Caregiver Well-Being

Well-being involves the affective feelings of the caregiver. As such it involves an assessment on the part of the caregiver as to how the positive and negative aspects of his/her life at present compare with one another. Andrews and Withey (1976) argue that there are three dimensions to well-being measures: positive and negative affect or feelings, life-satisfaction (a more judgmental assessment of one's entire life), and intensity of feeling. Affect was selected for the current study because it appears to be the well-being dimension most closely related to a burden measure evaluating caregiver perceptions of current changes in their lives as a result of providing care.

Well-being was measured with the Mental Health Inventory, which was originally designed for use in the nationwide Rand Health Insurance Experiment (Veit and Ware, 1983). Containing 38 items the full scale includes a general underlying psychological well-being factor, two correlated factors (psychological distress and well-being), and five correlated lower order factors -- anxiety, depression, emotional ties, general positive affect, and loss of behavioral or emotional control. The MHI has been used to predict use of outpatient mental health services (Wells, Manning, and Benjamin, 1986); general health services (Manning, Newhouse, and Ware, 1982), and in another large study to compare the well-being of six different types of chronically ill persons (Cassileth et al., 1984). More recently the MHI was used in a study of coping styles of women with rheumatoid arthritis (Manne and Zautra, 1989). The reliabilities reported for the scale in the studies just mentioned are from .96 to .97.

Each item on the scale asks subjects to indicate how much of the time during the past month they felt or behaved in a certain way. Scoring of the scale is done with a six point response set, ranging from "always" to "never."

Likelihood of Nursing Home Placement

This scale was designed for use in the current study. It consists of five items, asking the caregiver to express agreement/disagreement with statements presenting feelings about the probability of eventual nursing home placement for the care-receiver. Two of the items are similar to ones used by Whittick (1989) in her "pro-institutionalization aspects of caregiving" scale, but her work was not available at the time the scale was developed. Scoring was with a 4 point response set (strongly agree, moderately agree, moderately disagree, strongly disagree.) Higher scores indicate a stronger probability of future nursing home placement.

Other Information Collected

Basic Data

For subjects, standard information collected included age, sex, race, education, income, marital status, number of children, number of siblings, and employment. Subjects were also asked to evaluate their own health and say how it compared with other persons their own age. For the care-receiver, data were collected on relationship to the caregiver, age, major health problem, and living arrangement.

Additional Caregiving Information

Subjects were asked how long they had been providing care, whether they considered themselves to be the primary caregiver, what they did to assist the care-receiver, how many hours a week they provided help, whether they had reduced or adjusted their working hours (and if so, by how much) as a result of caring, and whether they were using adult day health, paid home care, respite care, or support group services. Subjects were also asked to list any unpaid person who was helping them, what that person did, and how many hours per week that person helped.

Conflict with Relatives in the Social Support Network

In order to augment the data supplied by the social support upset scale, several open-ended questions were asked. Caregivers who named a relative on the social support scale as being "somewhat" or "very upsetting" on any of the five dimensions were asked to describe what the nature of the problem was and how they had dealt with that person. If more than one person named had been so described, the one seen as most upsetting was used. This information allowed determination of the seriousness of the problem, the relationship of the upsetting person to the caregiver, the type of problem involved, and what the caregiver had attempted to do about it.

Caregivers who indicated that they were experiencing on-going conflict that was more than minor with a relative were so classified. Family conflict was defined as "a clash or strong feeling of resentment with or toward a relative about caregiving that is perceived as a serious problem by the caregiver." Such conflict has been mentioned in three other studies of adult child caregivers (Abel, 1989; Frankfather, Smith, and Caro, 1981; Hausman, 1979;) but only in general terms. Archbold (1980) did quantify her results, and reported that 50% of her adult child caregivers were having problems with siblings. The difficulty with Archbold's study is that her sample size was only six. Using a somewhat broader definition of conflict than the one used in the current study, Rabins, Mace, and Lucas 1982), reported that 56% of the adult child caregivers in their study were experiencing family conflict; the researchers did not, however, attempt to link such conflict with any caregiving outcomes. Barusch and Spaid (1989) reported a positive association between "adverse social contacts" (negative aspects of emotional support) and perceived burden for spouse caregivers, but their results were not significant. Brody, et al., (1989) examined inter-sibling hassles using a one item measure and reported that such hassles were positively related to caregiver perceived burden and negatively related to relationship quality. On a four point scale of such hassles (none/a little/fair amount/a great deal) the mean score was only slightly above "a little."

The measures used in the current study will allow both a quantification of family conflict and an analysis of its relationship with caregiving outcome variables.

Other Open-Ended Questions

Other open-ended questions included describing the greatest difficulty in providing care, the greatest satisfaction, whether others had pressured subjects to provide care (and if so, who that person was and how they had responded), what services should be provided to help them in caregiving, whether subjects felt in general that adult children should help take care of frail parents or in-laws when they became old and frail (and if yes, why they felt the way that they did,) and what, if anything, caregiving had taught them about how they might want to be treated if they were in a similar condition.

Decision Rules for Scoring

Intermediate scores were allowed (such as between strongly and moderately agree) and scored as the midpoint between the respective responses. Where answers were given in years (such as length of caregiving) fractional responses (such as eight months) were rounded off to the nearest half year. The one exception was age, which was rounded off to the nearest whole year.

Subjects with no spouse on the perceived caregiving burden item concerning experiencing increased tensions with spouses were coded "never a problem or concern." Other missing data/refuse to answer/not appropriate responses on scale items were few, occurring only once every two subjects. Those missing responses that did occur on scale items were recoded to the mean response on that particular item for all subjects so that reliability measures could be calculated.

For other than scale items, one caregiver refused to give the age of his care-receiver mother-in-law but did say that she was over 55. Two refused to answer the income question. Thirty-one caregivers were unable to precisely estimate the number of hours per week that they spent caregiving, although all of these said that it was more than four. Twenty-eight of them said that they were "full-time caregivers," while three said they were not full-time but were caring for more than four hours per week. This question proved difficult to answer for caregivers who had the care-receiver living with them. They knew how many hours per week they spent doing activities solely for the care-receiver, but it was hard for them to estimate how much extra time they spent on activities that they also did for other family members, such as cooking, laundry, and cleaning. Caregivers who did not live with the care-receiver could estimate the extra time more easily, because they knew how many hours they were away from home during a typical week. Thirty-three were unable to precisely estimate the number of hours per week that others in their support network spent helping them. Many of these persisted in saying "it varies" even when asked to estimate for the last week or month. Because of these difficulties, time estimates described in the results should be viewed with caution.

Sample Size and Power Analysis

The sample size of 100 was selected based partly on what was really feasible to accomplish and partly on power analysis calculations. Given the resources available for the study and the difficulty in subject recruitment, 100 subjects were the most that seemed reasonably attainable.

Power analysis revealed that a sample of 100 would have sufficient power to likely find moderately strong relationships among the variables in the study if in fact such relationships actually existed in the population under study. The power of a significance test is the probability that it will yield statistically significant results assuming that a given relationship in fact exists in the population being sampled (Cohen, 1977). In power analysis the issue is how likely a given design will produce a significant result if one in fact does exist. Assuming the use of a two-tailed test of significance with a significance level of .05 for the bivariate relationships, a sample size of 100 will have a power of 85% for a correlation of .30 or better and a power of 70% for a correlation of .25 or better. Such correlations represent "moderate" effects according to Cohen and are similar to those generally reported in the caregiving literature. Thus, if a moderate correlations of at least .25 to .30 actually exist between the variables proposed for analysis in the current study, a sample size of 100 will have a 70 - 85% chance of finding them.

Pretest

The questionnaire was pretested on eight persons who had recently been involved in caring for a parent. Based upon comments received from those being interviewed various wording changes were made to the instructions to make the interviews move as smoothly as possible.

Two persons said they felt uncomfortable answering the relationship quality items, so particular attention was paid to the preamble for this scale to make subjects feel more at ease discussing their parent or in-law in the presence of an interviewer. Several sentences were added saying that talking about a parent or inlaw could be difficult at times and that no one was trying to judge the caregiver or his/her feelings about the care-receiver. Once these changes were made, no subsequent difficulties were found administering the relationship quality scale.

Instructions were also revised to allow intermediate scores on all scales (such as between strongly and moderately agree). Since all eight individuals participating in the pretest scored relatively high on the duty scale, two additional items were added that would indicate a very strong sense of duty to care for someone. Based upon suggestions from the participants, one item that initially was used on the satisfactions scale was moved to the duty scale and one item (financial worries) was added to the perceived burden scale. Several redundant items were removed and several open-ended questions were added. The final revised questionnaire is the one that has been described in this chapter.

CHAPTER IV

RESULTS

This chapter presents the major results of the study, including a description of the sample, psychometric properties of the scales used, bivariate correlations between the independent and dependent variables, tests of the theoretical model, and tests of the revised model.

Sample Characteristics

The sample consisted of 100 adult children with a mean age of 51 years, although there was a wide range (29 to 70). These caregivers were predominantly female (83%), white (88%), and married (67%). The married category included two caregivers who were gay and lived with their partners. Education and income levels were relatively high with 78% having attended at least some college and 70% reporting an annual income of $24,000 or more. These data are presented in Table 4.

As Table 5 indicates, most (71%) were caring for a mother; 18% were caring for a father, 9% for a mother-in-law, and 2% for a father-in-law. The mean age of the care-receiver was 80 years (range 59 to 97). The care-receiver's main health problem was dementia (41%), followed by stroke (14%), cardiovascular disease (10%), "general frailty" (10%), arthritis (6%), mental problems (6%), cancer (4%), visual impairment (3%), and other (6%). The relatively high proportion of dementia in the sample probably reflects the fact that three of the nine referral sites catered to demented patients. Many care-receivers had multiple health problems -- the one indicated here was the main one reported by the caregiver.

Sixty-nine percent of these caregivers were employed and averaged 34

Table 4. Caregiver Sample Descriptive Data (n=100)

ITEM	NUMBER/%	ITEM	NUMBER/%
GENDER		MARITAL STATUS	
Male	17	Married/Partnered	67
Female	83	Divorced/Separated	15
		Never Married	10
		Widowed	8
EDUCATION		ANNUAL INCOME	
Not High Sch. Grad	7	Less than $15,000	11
High Sch. Grad	15	$15,000 - $24,000	19
Some College	43	$24,000 - $48,000	42
College Degree	20	Over $48,000	28
Graduate Degree	15		

AGE: Mean = 50.5 years S.D. = 8.9 Range = 29 - 70

Table 5. Care-Receiver Descriptive Data (n=100)

ITEM	NUMBER/%	ITEM	NUMBER/%
RELATIONSHIP to CAREGIVER		MAJOR HEALTH PROBLEM	
Mother	71	Alzheimer's/Dementia	41
Father	18	Stroke	14
Mother-in-Law	9	Cardiovascular Disease	10
Father-in-Law	2	General Frailty	10
		Arthritis	6
		Mental Problems	6
		Cancer	4
		Visual Impairment	3
		COPD/Emphysema	2
		Diabetes	2
		Multiple Sclerosis	1
		Osteoporosis	1

AGE: Mean = 79.9 years S.D. = 8.5 Range = 59 - 97 hours a week at work. One third (34%) said that they had reduced the number of hours they worked as a result of providing care; for these the average number of hours reduced per week was 19. Another 10% said that they had had to adjust their working hours (such as by using vacation leave for medical crises or by working at a different time of day than they used to) as a result of caring. Two of the adjustments involved switching to working at night in order to be with the care-receiver during the day. Two persons indicated that they had increased their working hours as a result of financial pressure stemming from caregiving. These data are presented in Table 6.

In terms of physical health, the caregivers generally perceived themselves as healthy (Table 7). When asked to describe their own health, 61% described it as very good or excellent, 25% described it as good, while 14% said their health was fair or poor . These figures are quite a bit higher than those reported for all American adult child caregivers, where 31% reported their physical health as fair or poor (Stone, Cafferata, and Sangl, 1987). When comparing their health to "other persons their own age," 49% felt it was better, 45% about the same, while only 6% described their health as worse than others.

Table 8 summarizes the caregiving activities of those in the sample. When asked who was the person most responsible for caring for the care-receiver, 73% named themselves, 5% named their spouses, 2% named the care-receiver's spouse, and 16% felt that caregiving activities were equally shared with someone else (usually a brother or sister). In four cases (4%) a non-family member was listed as the one primarily responsible, such as another older person involved in a home-sharing arrangement. A majority (56%) of the care-receivers actually lived with the caregiver; 29% lived alone, 7% lived with

Table 6. Caregiver Employment (n=100)

ITEM	NUMBER/%	ITEM	NUMBER/%
EMPLOYED?		CHANGED WORKING HOURS	
Yes	69	Reduced	34
No	31	Increased	2
		Adjusted	10
		No Change	54
HOURS WORKED		WORKING HOURS REDUCED	
Number Working	69	Number Who Reduced	34
Mean (Hours)	34	Mean (Hours)	19
Range	2 - 50	Range	2 - 50
S.D.	12.6	S.D.	15.8

Table 7. Caregiver Perceived Health (n=100)

ITEM	NUMBER/%	ITEM	NUMBER/%
DESCRIBE OWN HEALTH AS:		HOW HEALTH COMPARES TO OTHERS OWN AGE:	
Excellent	31		
Very Good	30	Better Than	49
Good	25	About the Same	45
Fair	9	Worse	6
Poor	5		

a spouse, and 8% lived in other arrangements, such as home-sharing, board-and-care, or rotating among several relatives. Where the caregivers could actually estimate the number of hours per week that they were providing care, the mean number of hours reported was 22. This figure is somewhat distorted, however, since it does not include the 28% who indicated that they provided "full-time care" but could not estimate the actual hours provided. It is difficult to

Table 8. Caregiving Activities Performed by the Caregiver (n=100)

ITEM	NUMBER/%	ITEM	NUMBER/%
PRIMARY CAREGIVER IS:		CARE-RECEIVER LIVES WITH:	
Subject	73	Subject	56
Equally Shared	16	Alone	29
Caregiver Spouse	5	With Spouse	7
Care-Receiver Spouse	2	Other	8
Other	4		
HOURS OF CARE PROVIDED PER WEEK		NUMBER OF YEARS CAREGIVER HAS BEEN PROVIDING CARE	
Number Reporting	69	Number Reporting	100
Mean (Hours)	22	Mean (Years)	5.2
Range	4 - 108	Range	0 - 43
S.D.	20.0	S.D.	6.8
NUMBER OF ADLs CAREGIVER PROVIDES ASSISTANCE ON		NUMBER OF IADLs CAREGIVER PROVIDES ASSISTANCE ON	
Number Reporting	100	Number Reporting	100
Mean	1.8	Mean	4.9
Range	0 - 5	Range	3 - 6

estimate such time with any precision when household activities like preparing meals, shopping, and doing laundry for other family members are combined with those connected with caregiving. Another 3% said they provided at least four hours of care a week but could also not estimate the actual amount. Many of the caregivers had been providing care for some time -- the mean was 5.2 years, but the range was very high (from two months to 43 years.) The latter case involved a woman who had been assisting her mentally ill mother since her young teens when she said her father told her she would have to help care for her mother.

For support on Activities of Daily Living (ADLs), the caregivers were asked whether they provided assistance on bathing, eating, dressing, walking, or toileting. Seventy-four percent of the caregivers helped with at least one The mean number of such ADL assistance was 1.8. Ten percent provided help on all 5 ADLs. For Instrumental Activities of Daily Living, the list included managing finances, shopping, preparing meals, doing housework, providing transportation, and helping with medications. The mean number of such IADL assistance was 4.9. The fewest number of IADLs that any caregivers provided assistance on from this particular list was 3; the most was 6.

Table 9 summarizes the potential availability of support from other family members. Over half (56%) had at least one living brother, while 60% reported at least one living sister (79% had at least one or the other.) As far as children were concerned, 81% had living children. For those with children the mean was 2.9 children each. Most of these children were grown and gone -- only 35% had children living at home at the time of the interview. In 8% of the cases the other parent was still alive, although in all but one of these this parent also required some assistance on the part of the caregiver. As previously noted in Table 1, 67% had a spouse or partner available.

Actual support received is summarized in Table 10. For paid help, 50% had paid care provided at home, 41% used adult day care, 15% belonged to a support group, and 6% made use of respite care (these latter four percentages are not additive since some caregivers used more than one service). All but 12% had at least one unpaid person (nearly always another family member) helping (mean = 1.8 persons, range 0 to 6); such help averaged 15 hours per week. Several of these caregivers were involved in rather elaborate networks to help their parent or inlaw stay independent. One was in a network of two

Table 9. Potential Availability of Family Support (n=100)

ITEM	NUMBER/%	ITEM	NUMBER/%
CAREGIVER HAS SISTER		CAREGIVER HAS BROTHER	
Yes	60	Yes	56
No	40	No	44
CAREGIVER HAS CHILDREN		CARE-RECEIVER SPOUSE ALIVE	
Yes	81	Yes	8
No	19	No	92

Table 10. Actual Support Received by the Caregiver (n=100)

ITEM	NUMBER/%	ITEM	NUMBER/%
USES PAID HOME CARE		USES DAY HEALTH CARE	
Yes	50	Yes	41
No	50	No	59
ATTENDS SUPPORT GROUP		USES RESPITE CARE	
Yes	15	Yes	6
No	85	No	94
HAS AT LEAST ONE UNPAID HELPER		NUMBER OF UNPAID HELPERS	
Yes	88	Mean Number	1.8
No	12	Range	0 - 6
HOURS OF UNPAID HELP RECEIVED			
Number Reporting	77		
Mean (Hours)	15		
Range	0 - 96		
S.D.	19.4		

sisters and a brother who lived 25 miles apart and took turns spending two or three nights a week each with their frail mother who still lived alone. Another was part of a group of five sisters who again took turns spending evenings with their mother in her home. Three other caregivers were involved in sibling networks where the care-receiver came to them for one or two weeks at a time. Such caregiving networks required extensive coordination. Other caregivers shouldered their caregiving tasks with little or no assistance from anyone else. Satisfaction with support received varied widely. As will be shown later, 40% reported fairly serious conflict or resentment toward another family member over caring for the care-receiver, and the most frequent complaint was that the offending relative was not providing enough assistance.

In percent female, age, hours of care provided per week, years that have been providing care, and living arrangements, the caregivers in the current study were comparable to those reported in a nationwide sample for adult child caregivers in 1982 (Stone, Cafferata, and Sangl (1987). Differences are that those in the current study are more likely to be white, have higher marriage rates, are more likely to be employed, are more likely to have reduced working hours as a result of caregiving, have higher incomes, and report better physical health.

In summary, this sample consisted of mostly middle-aged, female, white, well-educated, caregivers with above-average incomes who made use of some paid services and who had other family members potentially available to assist in meeting caregiving demands. These caregivers had been providing care for over five years and were generally providing a fairly extensive amount of care at the time they were interviewed. While most worked, over a third had reduced the number of hours that they worked in order to provide care while another

10% had adjusted their hours. In over half the cases the caregivers lived with the person they were caring for. The most frequent problem presented by the care-receiver was dementia, followed by stroke, cardiovascular disease, and "general frailty."

Other Non-Scale Variables

Caregiving Network

As previously indicated in Table 10, caregivers named a mean of 1.8 unpaid persons as actually helping them care for the care-receiver on a regular basis. For the social support questions subjects were first asked to add anyone whom they felt should be helping and anyone not named that they talked with on a regular basis about any worries or concerns connected with their caregiving. When these additional persons were added, the result was a mean of 3.2 persons (range 0 to 6).

Caregiver Support Upset

For each person named in the support network, caregivers were then asked how upsetting that person was on five different dimensions of social support. As previously noted, scoring was based upon the procedures recommended by Pagel, Erdly, and Becker (1987). Two caregivers who listed no one as helping were asked how upset they were that they in fact had no one to assist them . The mean score on this variable was 7.8 with a standard deviation of 2.7 and a range of from 5 to 17. The theoretical range is 5 to 20; a score of "5" means that all persons named in the support network are "not upsetting" on all five dimensions of support, while a score of "20" would mean that all named are "very upsetting" on all five dimensions. The number of caregivers indicating that no one in their support network was at all upsetting was 16; a histogram of the upset variable shows it to be skewed to the low end, with more caregivers reporting low levels of upset than high.

Caregiver Support Helpfulness

In order to test Pagel, Erdly, and Becker's contention that upset scores are more powerful predictors of caregiving outcomes than are helpful scores, caregivers were also asked to state how helpful each person named in the social support network was on the same five dimensions as the upset questions. The mean score achieved was 12.6, with a standard deviation of 3.7 and a range of 5 to 20, which was the same as the theoretical range. A score of 5 indicates that everyone named was "not helpful" on all five dimensions, while a score of 20 indicates that everyone named was "very helpful" on all five dimensions. The two caregivers who named no one on the social support scale were deleted for this comparison.

A comparison of correlations between the upset and helpfulness measures for the three caregiving outcome variables is presented in Table 11. Both variables were associated with caregiver perceived burden, caregiver well-being, and likelihood of nursing home placement in the expected directions. However, the upset measure was much more strongly associated with caregiver perceived burden and caregiver well-being than was the helpfulness measure. For perceived likelihood of nursing home placement the association was somewhat higher for the helpfulness measure.

Table 12 compares the two measures in multiple regression equations with caregiver perceived burden and caregiver well-being regressed on relationship quality, caregiving tasks, and either the upset or helpfulness score.

Table 11. Comparison of Upset and Helpfulness Measures on Three Caregiving Outcomes (n=98)

DEPENDENT VARIABLE	CORRELATION WITH UPSET	 HELPFUL
Nursing Home Placement	.17	-.23*
Caregiver Perceived Burden	.56***	-.34**
Caregiver Well-Being	-.48***	.24*

* p <.05 **p <.01 ***p <.001

Table 12. Comparison of Upset and Helpful Measures in Two Multiple Regression Equations (n=98)

REGRESSION EQUATION	BETA WEIGHTS WHEN EQUATION USES . . . UPSET	 HELPFUL
Caregiver Perceived Burden on Relationship Quality Caregiving Tasks and Upset or Helpful	.45***	-.25**
Caregiver Well-Being on Relationship Quality Quality, Caregiving Tasks and Upset or Helpful	-.44***	.21**

* p <.05 **p <.01 ***p <.001

Results are presented in standardized beta weights. In both cases the association with the upset measure was considerably stronger than with the helpfulness measure. It thus appears that measuring the degree of caregiver upset with those in the social support network has a stronger association with caregiving outcomes than does using degree of helpfulness.

Open-Ended Questions

Table 13 summarizes answers to the question about what the greatest burden or difficulty was in caring for the care-receiver. By far the two most frequent responses were difficulties in trying to balance caregiving with other activities (27%) and dealing with behavior problems on the part of the care-receiver, such as moodiness, negativity, difficulty making decisions, or violent acts (24%). Constantly feeling responsible for the care-receiver was mentioned by 9%. Only 7% of the caregivers in the current study, mentioned difficulty with personal care items (such as toileting) as the greatest difficulty they faced. Financial burdens and hassles with relatives were each mentioned by 5%.

Responses to the opposite question (what the greatest satisfaction in caregiving was) are summarized in Table 14. Tied for first at 27% were knowing that the care-receiver was receiving the best quality care and enjoying the care-receivers company or some particularly positive action, such as when the care-receiver smiled or made a statement that reminded the caregiver of how the parent or in-law used to be. Helping make the care-receiver happy was mentioned by 21% of the caregivers. Interesting enough, 5% said that they found no satisfactions in their caregiving.

In an effort to determine how much pressure these caregivers had felt to either start care in the first place or increase it once started, subjects were asked if they had felt any pressure from others around them to provide care for the care-receiver. The results are presented in Table 15. Only 12% said that they had felt initial pressure from relatives to start caregiving in the first place, such as having relatives send the care-receiver to them, say that they could not care for him or her themselves, or simply make it known that they expected the caregiver to be the one to provide care. Two of these caregivers had been told

Table 13. Greatest Difficulty in Caring for the Care-Receiver (n=100)

ITEM	NUMBER/%
Balancing caregiving with other activities	27
Dealing with care-receiver's behavior problems	24
Constantly feeling responsible for care-receiver	9
Difficulty with personal care of care-receiver	7
Financial burden of caring	5
Hassles with relatives	5
Seeing effects of dementia on care-receiver	5
Dealing with own emotions/reactions	4
Dealing with care-receiver's medical problems	3
Dealing with the unexpected	3
Other	8

Table 14. Greatest Satisfaction in Caring for the Care-Receiver (n=100)

ITEM	NUMBER/%
Knowing care-receiver is receiving good quality care	27
Care-receivers company, positive acts by care-receiver	27
Helping care-receiver be happy	21
Knowing that I am doing my best in caring	7
Just doing it, making it work	6
None	5
Other	7

Table 15. Felt Pressure to Start or Increase Care (n=100)

ITEM	NUMBER/%
Felt pressure from relatives to initiate care	12
Felt pressure from health professionals to initiate care	1
Felt pressure from friends to initiate care	1
Felt pressure from relatives to increase care once started	7
Felt no pressure to initiate care or increase it once started	79

by their fathers that they would have to eventually care for their mothers when their fathers died, one of which involved a death-bed promise. Two percent of the caregivers reported pressure to initiate care from other sources: one said she had been pressured by health care professionals to have her mother come and live with her, while another said he could not face his friends if he had not cared for his father. For the vast majority of these caregivers, however, the role of caregiver was assumed because they wanted to provide care, not because they felt pressured by anyone. For 7% of the caregivers, pressure from relatives came after caregiving began and consisted of pressure to do more for the care-receiver than they were presently doing. All in all, 21% of the caregivers reported pressure from other persons either to start care or increase it once started.

When subjects were asked whether adult children in general should be expected to care for their parents or in-laws when they became old and frail, 4% said that they should not, 71% said that they should, and 25% said that the answer depends upon the particular situation involved (usually the quality of the relationship that exists and the capabilities of the adult children to provide care.) Those who said that adult children should be expected to care for their parents or in-laws were also asked why they felt the way that they did. Results are shown in Table 16. Thirty percent gave reciprocity (because of what the parents or in-laws did for their children) as a reason, 28% said they just felt that it was the right thing to do or saw it as a general obligation, 21% felt that family care of frail elders was an integral part of the caring aspects of family life, 7% said that family care benefits the elderly person involved, 7% gave religious values as a reason, and 3% said that only families could provide quality care. Table 17 summarizes the responses when caregivers were asked what caregiving had taught them about how they might want to be taken care of if they were in a similar situation. The highest two categories were evenly split between those who said they wanted to be cared for by family members (32%) and those who said they would prefer some form of institutional care (32%). The kind of institutional care talked about was usually a retirement home or life-care facility, not a nursing home. Another 16% said that they wanted to remain completely independent as long as possible so as not to have to face the issue, 8% said that if they became dependent they wanted someone to "pull the plug," and 4% said that they preferred to be cared for at home by paid providers. While answering this question many of the caregivers expressed concerns about becoming a "burden" on other family members. Most of those preferring institutional care or care at home by paid providers still wanted family contact, while many of those opting for family care added the qualifier that they would try to make care by other family members as easy as possible. Several added that they had purchased long-term care insurance. One, noting that her care-receiver mother had said she did not want to be dependent upon family until

Table 16. Why Adult Children Should Care for Parents (n=71)

ITEM	NUMBER/%
Because of what parents/in-laws did for them	(21) 30%
Feel it is the right thing to do or general obligation	(20) 28%
Family care is an integral part of family life	(15) 21%
Family care benefits the elder being cared for	(5) 7%
Religious values	(5) 7%
Only families can provide quality care	(2) 3%
Other	(3) 4%

Table 17. How Caregivers Want to be Cared for Themselves (n=100)

ITEM	NUMBER/%
Prefer being cared for by other family members	32
Would prefer some sort of institutional care	32
Want to stay independent as long as possible	16
When get really dependent, "pull the plug"	8
Want to be cared for at home by paid providers	4
Want to be treated with respect wherever I go	2
Will try to be gracious for whatever care I receive	2
Other	4

she became frail and then changed her mind, remarked that while she did not want family care now, she too might feel differently if she became disabled.

Psychometric Properties of Study Scales

Psychometric properties of the scales used in the current study are presented in Table 18. The procedures for scale development involved deleting items which had low item-to-total correlations (less than .20) and negative inter-item correlations with more than two other scale items. However, the criteria for deletion were called into play only on the duty scale. In all other scales every item was maintained. As noted before, missing data were rare (on scale items only one item for every two subjects). Where data were missing the mean score for all other subjects on that particular item was substituted so that reliability tests could be run. Histograms of the scores on the scales showed that all of them approximated normal distributions.

Caregiving Tasks

This 15 item Caregiving Tasks scale achieved a standardized alpha coefficient of .86. The mean of 50 was quite close to the theoretical mean of 52.5. Scores ranged from a low of 23 to a high of 81; the lowest possible score would have been 15 (for someone who never did any of the 15 items); the highest, 90 (for someone who did all 15 items all of the time). Since subjects had to be providing certain minimum levels of care in order to take part in the study it would have been unlikely that anyone would have scored 20 or below. One item (extent to which provides transportation for the care-receiver) came very close to being deleted: its item-to-total correlation was .19, but it had negative correlations with only two other scale variables. The reason for its

Table 18. Scale Characteristics (n=100)

Scale	Number of Items	Mean	SD	Range	Standardized Coefficient Alpha
Caregiving Tasks	15	50.0	15.8	23-81	.86
Relationship Quality	22	67.4	13.1	35-88	.92
Duty	9	28.8	4.7	16-36	.78
Caregiving Satisfactions	15	43.9	8.1	20-60	.86
Caregiver Perceived Burden	22	49.0	13.7	26-86	.94
Caregiver Well-Being	38	157.9	33.7	66-218	.97
Nursing Home Placement	5	11.9	3.9	5-20	.76

relatively low item-to-total correlation is probably that at high disability levels (and hence high other task scores), care-receivers are unlikely to be doing much traveling and so little assistance on this particular item is needed.

Relationship Quality

Relationship quality was assessed using the Walker and Thompson (1983) intimacy scale adapted with the addition of five items. Although the scale had been used only with female subjects regarding their mothers (most of whom were living independently), it appeared to function well with a group of mixed gender caregivers and care-receivers. Both male and female subjects appeared comfortable using it to describe their feelings about their parents or in-laws. The only difficulty appeared to involve talking about a relationship with a parent with severe dementia. In such cases it was difficult at times to separate the present relationship (which was often poor) from the past (which may or may not have been poor.) Most of the questions deal with the present, but subjects with demented parents often made statements like, "Well, I don't really know what mother is thinking about now, but she used to love me so I will go by that." For future use with caregivers caring for a demented parent, clarification of how to answer when the present relationship is different from what it used to be may be necessary. In the current study most caregivers dealing with demented parents appeared to answer more in terms of the past.

The scale contained 22 items and had a standardized alpha of .92, which is similar to that obtained by Walker and Thompson with their original 17 items. The five additional items (one assessing similarity of values and four dealing with past aspects of the relationship) had item-to-total correlations consistent with the original items, indicating a consistency between present relationship quality and statements about how it was in the past. Higher scores indicate higher relationship quality. The mean of 67.4 was higher than the theoretical mean of 55. As the theoretical mean denotes relatively neutral feelings toward the care-receiver, the mean of 67.4 indicates that these caregivers generally felt positive about the parent or inlaw that they were caring for. Indeed, two caregivers scored the highest possible value (88); none scored the lowest (22). The scale did have a reasonably good distribution with scores ranging from 35 to 88. Twenty-one subjects scored below the theoretically "neutral" mean. Some of these caregivers clearly had poor relationships with their care-receivers. "I enjoy being with my mother about a minute a month," said one. Another commented that her mother had always been boring and still was. One caregiver had brought her father into her home only after he threatened to commit suicide if she did not; he subsequently called 911 for emergency help if she left him alone. Caregivers with a depressed or potentially violent care-receiver were often worried about the negative effects of the care-receiver's behavior on their families. Jarrett's (1985) point that caregiving is ultimately based upon mutual obligations and that it can take place in the absence of affection is relevant here. One out of five caregivers in the current study scored relatively low on the relationship quality scale, yet they were still providing care.

For the majority of the caregivers, however, relationship quality with the care-receiver was good. Some commented that their relationship had always been good, others enjoyed having the care-receiver still able to function as an integral part of their family, and some felt that the good past relationship carried over into the present even though the care-receiver was now so demented that he/she could no longer recognize them.

Duty

The Duty scale was the only scale where several items performed poorly enough to be deleted. Four of the original items had item-to-total correlations of less than .20 and were negatively correlated with more than two of the other items; these were deleted for failing to meet the preset criteria. As discussed in the Methods Chapter, this scale was designed to measure specific aspects of duty (relative to the parent or inlaw) rather than more general feelings about the general obligation to care for a parent or inlaw. Three of the four items deleted were general duty items that had been added for comparison purposes. The low and negative correlations of these items with others in the scale suggest that there is a difference between feelings about caring in general vs. caring for the specific individual involved. The fourth item deleted dealt with feeling that the care-receiver should rely more on his/her own resources rather than expecting help from the caregiver; given the relatively high levels of dependency in the current study many subjects felt that this item was inappropriate and had difficulty answering it.

The revised 9 item scale had a standardized alpha of .78, a mean of 28.8, a theoretical range of 9 - 36, and an actual range of 16 to 36. The theoretical mean, 22.5, indicates that the caregiver was neutral with respect to feelings of obligation about caring for the care-receiver. The scores indicate that these caregivers generally agreed that they felt obligated to provide care to the care-receiver; but, as with the relationship scale, there was sufficient variation to show that obligatory motives for care do differ from one caregiver to another and that some caregivers feel only minimal levels of obligation.

Caregiving Satisfactions

The 15 item Caregiving Satisfactions scale achieved a standardized alpha of .86, a mean of 43.9, and a range of 20 to 60. With a theoretical mean of 37.5 (neutral with respect to caregiving satisfaction) and a possible range of 15 to 60, the scores in the current study indicate that, on the average, the caregivers interviewed generally found satisfactions in what they were doing. As with the other scales, however, there was a good deal of variation.

Caregiver Perceived Burden

The 22 item Caregiver Perceived Burden scale was designed to measure the extent to which caregivers see the changes taking place in their lives from their caregiving as problems or concerns. The scale achieved a standardized alpha of .94, a mean of 49.0, and a range of 26 to 86. Higher scores indicate higher levels of perceived burden. The mean of this scale fell somewhat above the theoretical mean (44), a score that would indicate each item averaged "somewhat a problem or concern" for the caregiver. These data are consistent with the earlier discussion that taking care of a disabled parent is generally perceived as burdensome. The possible range of scores on this scale is 22 (every item "never a problem or concern") to 88 (every item "always a problem or concern"). Actual scores nearly ranged across the entire scale, indicating that caregiver perceived burden varied greatly across the sample.

Caregiver Well-Being

Caregiver well-being was measured with the Mental Health Inventory. The standardized alpha was a high .97, exactly the same as reported by Veit and Ware (1983) in their description of the scale and by Manne and Zautra (1989) in their study of arthritis patients and their caregivers. The mean score of 157.9 is particularly interesting, since it is 20 points below the mean achieved when the scale has been administered to large numbers of adults in the general population (Veit and Ware, 1983). The lower results here may reflect the burdensome aspects of caregiving for the caregivers in the current study. Scores below 120 (scored by 15 of the caregivers in the current study) are comparable to those scored by persons with a clinical diagnosis of depression in one particular study (Cassileth, et. al., 1984). One advantage of the Mental Health Inventory is its broad range, and that feature was notable here as well; the standard deviation was 33.7 with a range from 66 to 218.

Likelihood of Nursing Home Placement

The Likelihood of Nursing Home Placement five-item scale achieved a standardized alpha of .76. Higher scores indicate higher agreement by caregivers that their care-receivers may eventually be placed in a nursing home. The mean of 11.9 is quite close to the theoretical mean of 12.5 (relatively neutral on average with respect to eventual nursing home placement.) Scores ran the full limit of the range of the scale from 5 to 20.

Of particular interest was the ease with which these perceived nursing home placement data were collected. The caregivers in the current study were quite willing to talk about their feelings, and many indicated that they had given the matter considerable thought. Feelings in both directions were quite strong for many subjects. Some said they had worked in nursing homes and would not want their parent or in-law to be there. Several so objected to the quality of care in nursing homes that they refused to institutionalize the care-receiver under any circumstances. "It will kill me if I have to take care of mother in my own home, but I'll do it if I have to," said one, who at the time of the interview had bought a separate home for her mother to live in nearby. Another said: "Keeping my mother out of a nursing home gives me some degree of satisfaction even though I hate every minute of it." Others enjoyed caring for the care-receiver and/or did not feel excessively burdened and saw no reason to consider institutionalization. Some indicated that certain actions on the part of the care-receiver would tip the scales, such as "If dad gets violent with my children he's going to a home." Still others said that they were reaching the limit on what they could do and were thinking about placement. Finally, there were those who felt that their care-receivers would be better off in a nursing home even though the present overall burden level was manageable. "I'll be able to sleep better nights knowing that dad and mom are safe," said one subject who with her sister could manage the physical care of her parents who lived nearby but who worried about their safety at night.

Impact of Family Conflict

Fifty-eight caregivers who reported a family member as "somewhat" or "very upsetting" on the social support scale were asked to describe the nature of the problem with that person and how they had tried to deal with him or her. Where more than one relative had been named, the one causing the greatest upset was used. Forty caregivers met the definition of family conflict ("a clash or strong feeling of resentment with or toward a relative about caregiving that is perceived as a serious problem by the caregiver") and were so classified.

Table 19 summarizes the relationship of the offending relative to the caregiver. By far the most frequently named person was a sister (35%) or brother (30%) followed by a spouse (20%), child (5%), other parent (5%), and sibling-in-law (5%).

The causes of the conflict from the caregivers' perspective are summarized in Table 20. One answer predominated: the relative would not provide sufficient help in caring for the care-receiver (60%). The next most frequently mentioned problem was a relative criticizing what the caregiver was doing for the care-receiver (12%), such as constantly calling with unwanted advice, being generally obnoxious, or accusing the caregiver of providing poor care. Relatives who insisted that the care-receiver be institutionalized (10%) constituted the third most frequent conflict. Part of the difficulty for the caregiver in this last category was the implication that these relatives would not provide further help unless the caregiver complied.

Three other types of conflict (relative is taking advantage of care-receiver, relative thinks caregiver does too much, and relative not visiting care-receiver) were each mentioned by two caregivers (5%). The first of these involved sisters who had moved back in with the care-receiver and who were felt by the

Table 19. Relative's Relationship to the Caregiver (n=40)

RELATIONSHIP	NUMBER/%
Sister	(14) 35%
Brother	(12) 30%
Spouse	(8) 20%
Child	(2) 5%
Other parent	(2) 5%
Sibling-in-Law	(2) 5%

Table 20. Type of Conflict Reported (n=40)

TYPE	NUMBER/%
Relative will not help with caregiving	(24) 60%
Relative criticizes caregiver's care	(5) 12%
Relative wants care-receiver institutionalized	(4) 10%
Relative is taking advantage of care-receiver	(2) 5%
Relative thinks caregiver does too much	(2) 5%
Relative will not visit care-receiver	(2) 5%
Relative and care-receiver argue all the time	(1) 2%

Table 21. Selected Demographic and Caregiving Variables Comparing Those With and Without Family Conflict (n=100)

MEASURE	WITH CONFLICT (N=40)	WITHOUT (N=60)	SIGNIFI-CANCE
Caregiver Gender (% Female)	92	77	p<.05*
Caregiver Age (Mean years)	48	52	p<.05**
Caregiving Tasks (Mean score)	52	49	NS
Number of Unpaid Helpers	1.5	1.8	NS
Weekly Hours of Unpaid Help Received	13	16	NS
Number of ADLs Assisting on	2.1	1.8	NS
Years Caregiver Has Been Caring	6.3	4.5	NS
Care-Receiver Dementia	40%	42%	NS

* Chi-Square **T-Test

caregivers to be taking advantage of their parents by not paying for room and board. The second situation (relative thinks caregiver does too much) was a problem because it involved husbands who wanted the caregiver to spend more time with them rather than with the care-receiver. The third type of conflict involved grown children (grandchildren to the care-receiver) who would no longer come over to see the care-receiver once she became demented.

Finally, one caregiver reported that another relative always got into arguments with the care-receiver. "Whenever she says, 'yes,' he says, no,'" she said. This last situation was a problem for the caregiver because the relative was her husband and the care-receiver his mother. Since they could not get along at all, much of the care fell on her.

Table 21 compares those experiencing conflict with those not experiencing conflict on selected demographic and caregiving data. While not significant, the problem with relatives not helping shows itself in the lower number of unpaid helpers reported by the conflict group, the higher scores on the task scale, ADL support provided, and hours of care provided per week. Those experiencing conflict had also been providing care for 1.7 years longer than those reporting no conflict, but this result was not significant either. The only significant differences in this table were on sex and age. Those experiencing conflict were more likely to be female and were four years younger on the average than those not experiencing conflict. The fact that care-receiver dementia played no part in family conflict is surprising, since drastic personality changes on the part of the care-receiver would seem a likely excuse for other relatives to pull away or recommend institutionalization.

Many of these conflicts and resentments reported were quite strong. Two cases resulted in legal action. One woman described her in-laws as "vultures" for only being interested in her father-in-law's money and never helping; another said that her family "had never been farther apart" while a third remarked "Don't ever try to care for a parent, because it can ruin your family relations." In 20% of the cases the caregiver indicated that the offending relative had caused some problems in the past, so the current conflict was partly anticipated but obviously not accepted. Indeed some of the caregivers not reporting conflict indicated in passing that there was a relative in the family who did not help but whom they did not expect to do anything because of past behavior. In 80% of the cases the conflict or resentment was recent, such as a sister who had offered to care for the care-receiver in exchange for being given her house to live in but had then tried to institutionalize her and simply take the house. This type of recent conflict reflects Pagel, Erdly, and Becker's idea that social support upset impacts mental health because it is the result of something expected but not received and hence is more powerful than measuring levels of satisfaction with something expected and received to varying degrees (1987). Recalcitrant siblings seemed to cause particular problems because caregivers felt they had grown up together, knew each other well, and should have been able to work things out. "I just do not understand my sister anymore," said one caregiver. "We used to be so close and now we don't speak to each other. It greatly upsets me." Another caregiver said this about her brother who had told her he would not help her care for their mother: "It's his warped sense of values. But we had a good relationship in the past until this happened. Now I don't talk to him anymore."

When asked to describe their own health, 22.5% of the caregivers with conflict described it as "fair" or "poor," compared with only 8.3% of the caregivers not experiencing conflict ($p<.05$, Chi-Square). Table 22 presents

Table 22. Impact of Conflict on Caregiving Outcomes (n=100)

Measure	Mean Score for Group: With Conflict (N=40)	Mean Score for Group: Without Conflict (N=60)	Significance
Relationship Quality	61.2	71.5	p<.001*
Caregiver Perceived Burden	56.0	44.3	p<.001*
Mental Health Inventory	144.2	167.1	p<.01*
Likelihood of Nursing Home Placement	13.0	11.2	p<.05**
Describe Own Health as Fair or Poor	22.5%	8.3%	p<.05**
Prefer Family Care Alternatives	17.5%	55.0%	p<.001**

* T-Test **Chi-Square

these results and other data describing the impact of family conflict on these caregivers. Those experiencing family conflict scored significantly higher on caregiver perceived burden and likelihood of nursing home placement and significantly lower on relationship quality and on the Mental Health Inventory than did those caregivers not experiencing family conflict. These differences remained significant when the same analysis was done with analysis of variance controlling for caregiving tasks. Those with conflict were also significantly less likely to state a preference for family care for themselves should they become frail or disabled . Alternatives preferred included retirement complexes, paid home care, congregate care, "pulling the plug," and nursing homes.

An early indication that conflict with relatives over caregiving is likely to occur may be when the caregiver feels pressure from other relatives to initiate care in the first place. Table 15 presented data showing that 12% of the caregivers had felt such pressure. Nine of the 12 (67%) also experienced subsequent conflict with relatives over the caregiving; in five cases the conflict was with the same relative, while in four cases it was with a different one. Being pressured to become a caregiver may set the stage for subsequent conflicts.

Path Analysis of the Hypothesized Model

Zero-order correlation coefficients for the variables in the hypothesized model are presented in Table 23. A diagram of the hypothesized model can be found in the Conceptual Framework Chapter (Figure 1.)

In addition to the variables in the hypothesized model, correlation coefficients were calculated for those descriptive and caregiving variables (Tables 4-8) that, while not part of the model, might be appropriate candidates for addition to it. Those variables so tested were caregiver age, caregiver gender, caregiver income, and care-receiver major health problem (coded as a dummy variable for dementia/not dementia). Caregiver gender was not significantly associated with any of the variables in the model, although its relationship with caregiver perceived burden came close ($r = .18$, $p \leq .06$) as women caregivers were reporting somewhat higher burden scores than men. The other three variables yielded five significant correlations: caregiver age was associated with lower perceived burden ($r = -.20$, $p < .05$); caregiver income was negatively associated with caregiving tasks ($r = -.27$, $p < .01$), lower perceived burden ($r = -.24$, $p < .05$), and greater caregiver well-being ($r = .30$, $p < .01$); and care-receiver dementia (coded as a dummy variable) was associated with greater likelihood of nursing home placement ($r = .19$, $p < .05$). Caregiver age, income, and care-receiver dementia were therefore added to the model for testing.

Table 23. Zero-Order Correlations Among Variables in the Hypothesized Model (n=100)

Variable	1	2	3	4	5	6	7	8
1. Caregiving Tasks	—	.03	.21*	.12	.02	.40***	-.28**	.18
2. Relationship Quality		—	.36***	-.28**	.60***	-.34**	.18	-.26**
3. Duty			—	-.09	.43***	.03	-.05	-.34**
4. Caregiving Support Upset				—	-.17	.56***	-.49***	.19
5. Caregiving Satisfaction					—	-.22*	.16	-.17
6. Perceived Caregiving Burden						—	-.71***	.33**
7. Well-being (Mental Health Inventory)							—	-.24*
8. Likelihood of Nursing Home Placement								—

* $p < .05$ **$p < .01$ *** $p < .001$

Path analysis was used to test the hypothesized model. Originally developed for use in biology by Sewell Wright, path analysis is a way of interpreting multiple regression coefficients, which, treated as path coefficients, can then be used to estimate the direct and indirect effects of selected variables on other variables to be explained (Mueller, Schuessler, and Costner, 1977). Path analysis makes causal assumptions explicit, as in the path model represented in Figure 1, and effects are estimated using those assumptions and the empirical data. The results thus constitute stronger claims than are entailed in ordinary multiple regression, in which the causal structure among predictors remains unspecified. An underlying assumption is that the model is recursive in that all variables are hierarchically arranged so that the assumed affects are all in one direction. No variable is assumed to have any effect on any prior variable in the model. Exogenous variables (those with no arrows going towards them) are assumed to be not highly correlated and to be not explained by the current theory or model.

The actual model testing procedure utilized a series of tests involving the proposed relationships shown in Figure 1 and the additional three variables discussed above. Each endogenous variable (with arrows pointing towards it) was regressed separately on its appropriate set of predictor variables. The procedure starts with the dependent variable (likelihood of nursing home placement) and then moves to the left. Multiple regression using forced entry was the procedure used; the resulting significant coefficients (if any) were compared with the appropriate hypothesis of a positive or negative multiple regression coefficient. If all hypothesized paths (direct and indirect) between a variable and the dependent variable were not significant, that variable was dropped from the model. Variables with no proposed paths between them were tested against a null hypothesis of no relationship (i.e., the multiple regression coefficients will equal zero) when the hypothesized relationships had been first controlled. If any of these no relationship paths proved to be actually significant, that particular path was added to the model. Procedures were then repeated with the addition of the three descriptive and caregiving variables discussed above. Standard .05 criterion for significance was used throughout the analysis. Regression coefficients are presented as standardized beta weights (B) to compensate for the different units of measurement used by the different scales.

An actual example may be helpful here to clarify the procedures used. The first regression involved likelihood of nursing home placement, which was regressed on perceived caregiver burden and caregiver well-being as hypothesized in the model. In this case the relationship between likelihood of nursing home placement and caregiver perceived burden ($B = .32$, $p < .05$) was significant and positive, as hypothesized in the model. But the relationship between likelihood of nursing home placement and caregiver well-being ($B = -.01$, $p \leq .94$) was not significant. In fact, caregiver perceived burden explained the same percentage of the variance in likelihood of nursing home placement by itself (11%) as when caregiver well-being was added to the equation. Since caregiver well-being no longer had any direct or indirect paths leading to the dependent variable (likelihood of nursing home placement), it was deleted from the model. Likelihood of nursing home placement was then regressed on all five of the other variables to the left of caregiver perceived burden. The result was that one association was significant (the relationship between duty and likelihood of nursing home placement ($B = -.37$, $p < .001$)), so that path was added to the model.

Similar procedures to those used in the above example were used on all endogenous variables. Exogenous variables (those with no arrows going towards them) were tested for multicollinearity, where the hypothesis was that they would not be highly correlated.

When the first round of testing procedures was completed, one other variable (caregiving satisfaction) was deleted. The hypothesized link between caregiving satisfaction and caregiver perceived burden was not significant when caregiver perceived burden was regressed on caregiver tasks, relationship quality, duty, and caregiving satisfaction. Dropping this path meant that caregiving satisfaction had no direct or indirect association with likelihood of nursing home placement, so it too was deleted.

All other variables in the hypothesized model were retained, but two of their hypothesized paths were deleted. The hypothesized relationship between duty and caregiving tasks was not significant; neither was the hypothesized relationship between relationship quality and caregiving tasks . These two paths were thus deleted from the model.

Two paths were added: the one described in the above example (a negative relationship between duty and likelihood of nursing home placement) and a negative relationship between relationship quality and caregiver support upset. The signs of paths which remained in the model were all in the hypothesized directions.

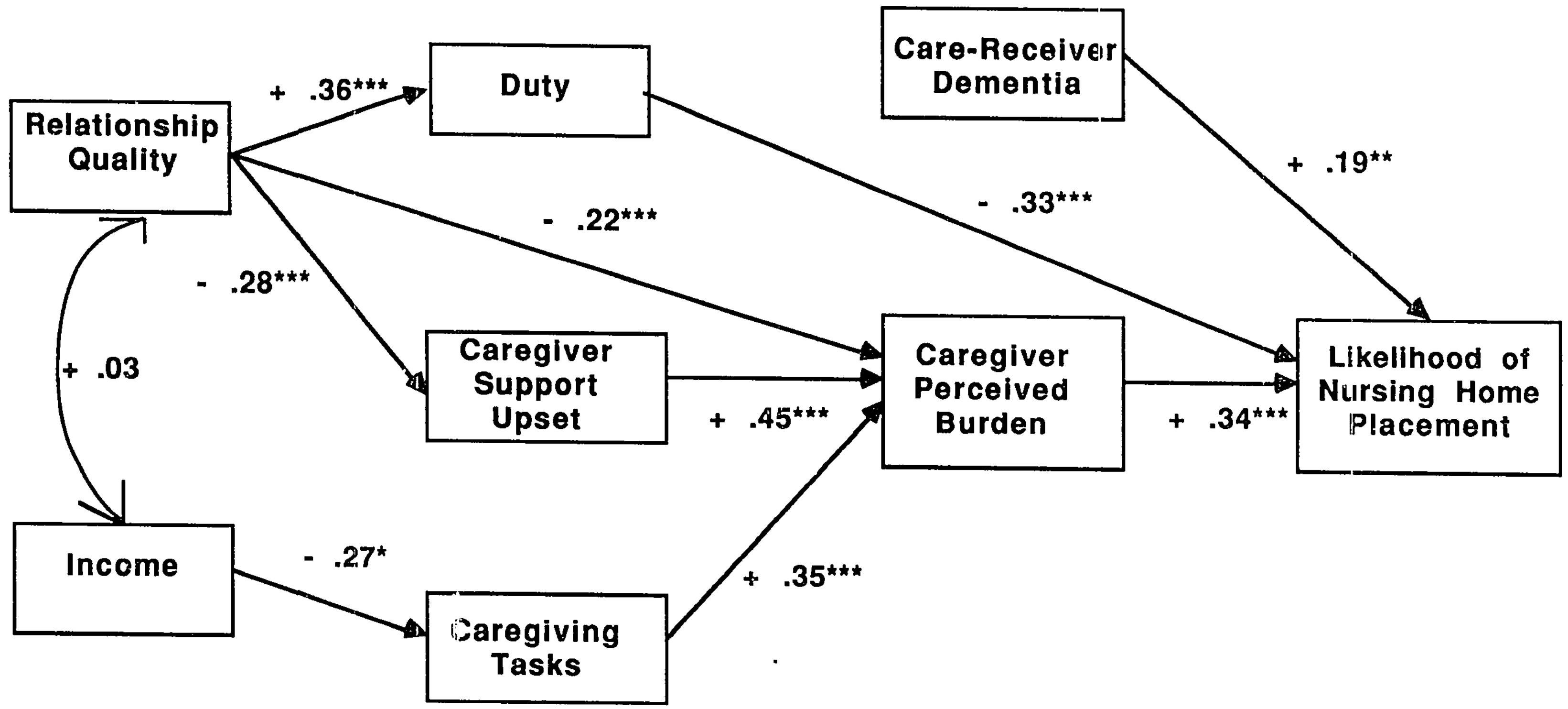
When caregiver age, caregiver income, and care-receiver dementia were added to the model for testing, other changes occurred. Regressing perceived burden on caregiver age was not significant when the other three variables with significant paths to burden (caregiving tasks, caregiver support upset, and relationship quality) were added to the equation. Caregiver age was thus deleted The relationship between care-receiver dementia and likelihood of nursing home placement remained significant with the addition of perceived burden and duty, so care-receiver dementia was retained in the model. Income was also retained, although the only significant path that remained was with caregiving tasks.

After deleting caregiver well-being and caregiving satisfaction, adding income and care-receiver dementia, and revising the hypothesized paths, the revised model was then retested. This revised model with its associated beta weights and significance levels is shown in Figure 2.

Likelihood of nursing home placement was associated with three variables: care-receiver dementia (B = 0.19, $p < .05$), perceived burden (B = .34, $p < .001$), and duty (B = -.33, $p < .001$). Combined these three variables explained 27% of the variance in likelihood of nursing home placement. Both caregiver support upset and caregiving tasks had indirect effects on likelihood of nursing home placement through their relationship with caregiver perceived burden, while income had an indirect effect through its relationship with caregiving tasks.

Perceived caregiving burden was also associated with three other variables: relationship quality (B = -.22, p < 01), caregiver support upset (B =. 45, $p < .001$), and caregiving tasks (B = .35, $p < .001$). Combined these three variables explained 47% of the variance in caregiver perceived burden. Income had an indirect effect on caregiver perceived burden through its effect on caregiving tasks. Duty had neither a direct nor an indirect effect on caregiver perceived burden.

Duty was associated with one variable, relationship quality (B = .36, $p < .001$), which explained 13% of the variance in duty.



*p<.05 **p<.01 ***p<.001

Figure 2. Revised Model with Significant Paths and Beta Weights

Caregiving support upset was associated with relationship quality (B = -.28, p <.01), which explained 8% of its variance.

Caregiving tasks was associated with income (B = -.27, p < .01), which explained 7% of its variance.

Multicollinearity does not appear to be a problem in the revised model. The two exogenous variables of relationship quality and income were not correlated (r = .03, p ≤ .77). Neither were any of the predictor variables in the second column of the model (duty, caregiver support upset, caregiving tasks, and care-receiver dementia.) The correlations among these last four variables were already presented in Table 21.

Additional Tests of Caregiving Satisfactions

Caregiving satisfactions was highly correlated with relationship quality, and some caregivers remarked while responding to the satisfactions scale that they found caregiving more or less satisfying based upon how well they got along with the care-receiver. A possibility exists, then, that the two variables are really measuring much of the same thing with relationship quality simply doing a better job. To further test this idea, the four variables that had a zero-order relationship with both relationship quality and caregiving satisfaction were each regressed on both variables at the same time. In every case except with duty the relationship between caregiving satisfaction and the other variables was not significant when relationship quality was thus controlled. These results suggest that a major component of caregiving satisfaction is the relationship quality with the care-receiver, and that the latter measure is a more powerful tool for examining caregiving outcomes.

CHAPTER V

DISCUSSION

This chapter delineates the limitations of this study, discusses various aspects of the results obtained, and suggests avenues for further research.

Limitations in The Study Design

Limitations of the current study include its cross-sectional design, non-random selection of subjects, and reliance upon self-reported data.

Caregivers were interviewed at one point in what for many is a long experience. Inferences were made about key variables in their activities that are presumed to be ongoing. The study did not employ a random design. It drew from caregivers who had contacted a day care program, home health agency, or referral program of some sort. The information gained was subjective: the caregiver's opinion was what was recorded; there were no other measures, and no effort was made to corroborate any of the information received. No doubt some of the recalcitrant relatives would have their own stories to tell. Furthermore, the principal variable of interest was likelihood of nursing home placement -- how closely it is related to actual nursing home placement is not known, although it is known that perceived burden is related to subsequent nursing home placement (Zarit, Todd, and Zarit, 1986.)

The limitations just cited are common in caregiving research, but they do mean that the results reported here are tentative. The problem of recording only the caregiver's opinion is partly mitigated by the fact that most of the relationships being tested involved variables where perceptions were important and hence corroborating information was not needed.

Balancing the limitations are this study's strengths. It involved a fairly large number of subjects, included caregivers from two states and both rural and urban areas to be as representative as possible, and used research instruments honed to the hypotheses to be tested. It used path analysis, a method which forces the researcher to think carefully about the relationships of the variables involved. The subjects appeared to take the study seriously; many had to juggle difficult schedules in order to be interviewed, and most answered the questions with thought and conviction. Clearly caregiving had become a major part of their lives, and they wanted to say how they felt.

Caring for a Parent is Burdensome and Impacts Mental Health

While caring for a frail, elderly parent is often described as burdensome and stressful, the 20 point difference scored by caregivers in this study on the Mental Health Inventory compared to a large sample of adults in the general population gives an indication of just how stressful it can be. The mean on the perceived caregiving burden scale suggests that many of the 22 items were at least "somewhat a problem or concern" for the caregivers in the study. Caregiver Perceived Burden was highly correlated with the Mental Health Inventory ($r = .71$, $p < .001$). Caregiver perceived burden thus explained 51% of the variance in mental health for the caregivers in this study. Since the Mental Health Inventory has been associated in other studies with the use of both mental health and general medical services, caring for frail, elderly parents has implications for the delivery and cost of health care services as well as an impact on the adult child caregivers themselves.

According to Miller (1981), adult child caregivers experience particularly high levels of stress. Caregiving comes at a time of changing roles and responsibilities with their spouses, children, and employment and often involves a shift in how they interact with the care-receiver. Certainly some of these caregivers were under great stress, trying to balance demanding jobs or difficult family situations with their caregiving efforts. Some were angry about what they saw as an uncaring society. One male caregiver who was an advertising executive, for example, was questioning the emphasis of the advertising industry on youth and consumption and was trying to counter such an emphasis by becoming more active in senior citizen advocacy groups. Several were angry with groups that they had expected to help (such as their parents' churches) which had instead pulled away. Some deeply resented the time commitment needed for caregiving. As one caregiver put it: "Some retirement, huh? All I do is take care of my mother and babysit for my children."

Since only adult children were included in this study, it is impossible to compare their mental health scores with spouse caregivers, but it would certainly be interesting to see if providing care for a frail spouse has as serious an impact on mental health as does caring for a parent. Some data indicate that scores on quantitative measures of subjective symptoms of stress may be low in spouse caregivers even when these same caregivers verbalize how difficult their caregiving situation is (Wallhagen, 1988, 1990). Use of the Mental Health Inventory in a study of both child and spouse caregivers would facilitate such a comparison.

As with nearly all of the measures used in this study, however, there was wide variation. Some caregivers experienced little burden and evidenced excellent mental health. Some were quite pleased with their caregiving efforts, such as one who had designed her new home around her mother's caregiving needs and showed it off to the interviewer with obvious pride. Others seemed to experience caregiving as simply one more thing to do in a life full of demands and uncertainties.

Value of a More Sharply Focused Perceived Burden Measure

The perceived caregiving burden scale used in this study was designed to measure the extent to which subjects perceived the changes occurring in their lives as a result of caregiving as problems or concerns. As such it was different from the very broad burden scales more generally employed in caregiving studies, the most commonly used of which is the Zarit scale (Zarit, Reever, and Bach-Peterson, 1980). Zarit's scale does have a few items on life-style changes, but it also includes caregiver health changes, desire for more money, relationship quality with the care-receiver, concerns about one's own reactions to the care-receiver, resentment toward relatives who are not helping, feeling that the care-receiver is too demanding, regrets about the past, fear for the future, desire for a better relationship with the care-receiver, feeling manipulated, and not feeling appreciated. With such an incredibly broad scale, it is no wonder that its reported relationship to other variables of interest has been relatively weak. When it does differentiate between different groups, it is also hard to know exactly what is being measured. Furthermore, Zarit's scale is scored in terms of amount of caregiver agreement with each item. As noted in the Methods Chapter, caregivers may agree with an item such as "I feel my mother is dependent," but not really perceive the item as a problem. The scale used in this study focused on what was hypothesized to be important for anticipating nursing home placement and measured perceived burden in terms of the extent to which it was seen as a problem or concern. The relationships between this variable and the other variables of interest are partly a result of its focused design. It performed well and deserves further testing and refinement.

Caring for a Parent May Cause Family Conflict

Forty percent of the subjects in this study indicated that they were having a relatively serious conflict with or resentment toward another family member over their caregiving activities. By far the most likely relative to be causing the problem was a sibling, and the problem usually involved the unwillingness of the sibling to provide sufficient help. The greatest anger seemed directed towards those siblings who had been expected to help by the caregiver and then did not. Often the caregivers were baffled by the behavior of the offending relative; they had thought they understood the person, but now they were not so sure. How could someone they had grown up with and known for a long time suddenly behave in such an uncaring way? A sense of being wronged, of justice denied ran through their comments. It may be that caregiving is demanding enough to intrude into carefully prescribed and ritualistic relationships so that family members see a very different, hidden side of one another -- one that they may or may not not like. The brother who was nice because he was mostly seen only at Christmas and Thanksgiving is now thrust into a very different situation and responds in surprising ways only because he had been experienced in such circumscribed ways for so long. Or it could be that demanding situations change people and relationships -- some for the better, some for the worse.

Some of these conflicts became quite heated and led to the breaking off of relations or even legal action. Such conflict had an impact on perceived caregiving burden, mental health, likelihood of nursing home placement, and caregiver's own report of health status. Caregivers experiencing family conflict were significantly more likely to prefer institutional alternatives for their own care should they become frail than were those without such conflict. If the results here are representative, family conflict is an important aspect of the caregiving experiences of adult children and merits more serious study.

The association between family conflict and relationship quality raises the question of which is the cause and which is the effect. The conflict with its attendant strain may spill over into the relationship between the caregiver and the care-receiver, or it may be that caregivers with better relationships with their parents or in-laws either expect less help from other family members or tend to overlook it more when it does not materialize. The latter explanation makes more sense if relationship quality is seen as a relatively stable variable carrying over from the past. Only a longitudinal study could resolve the causal direction.

It would be interesting also to compare families in some depth that seem to pull together so well with those that do not. There were several families in this study where caregiving appears to have actually improved family relationships, similar to the effects noted by Chenoweth and Spencer (1986). One caregiver mentioned improved relations with her brother and sisters as the greatest satisfaction that she had experienced ("We learned more about the particular skills that each of us has and came to appreciate each other more.") Several others mentioned the positive effects on their children of having a grandparent in the home and the importance of caregiving serving as a model of caring. Another mentioned how much caregiving had matured her younger sister and how quickly she had accepted her share of the responsibilities. As noted in the Results Chapter, several of the families involved had gone to extraordinary lengths to care for their parent, such as rotating nights spent at the care-receiver's home or alternating weeks in having the care-receiver stay with them. Learning how such families are able to pull together while others seem to move farther apart would add to the understanding of the process of family conflict.

One precursor for the existence of at least some of the conflict and resentment reported is that it began with the caregiver being pressured by relatives to care for the care-receiver in the first place. Twelve percent of the caregivers reported feeling pressure from relatives to begin providing care to the care-receiver in the first place and 9 of them (67%) also reported subsequent conflict or resentment. In five of these cases the subsequent conflict was with the same person. While most caregivers with conflict did not start out by being pressured to provide care, the relatively high proportion of those who were initially pressured and then subsequently experienced conflict at least suggests that early pressure may be a clue that problems lie ahead.

Clarifying expectations at the start of caregiving among the various family members who will be called upon to play a part may be helpful to avoid some of the conflict and resentment found in this study, and counselling sessions or family conferences may help caregivers deal with the problems once they occur. But part of the problem is that few caregivers really know what they are getting into when they start providing care to a parent or in-law. Helping a parent through an operation or other time-bound crisis is quite different from spending years dealing with someone with a chronic illness or increasing frailty. The average amount of time spent providing care by the subjects was over five years, a long time to expect various family members to sacrifice other important activities in order to provide care. Family conflict and resentment may be an unavoidable aspect of caregiving for many families.

Redundancy of Caregiving Satisfactions

Caregiving satisfactions is a relatively new variable in caregiving research, having made its appearance as a scale only several years ago (Kinney,1988; Miller, 1988; Moss, 1988;). The results in this study suggest that a satisfactions scale is measuring much the same construct as is relationship quality but in a weaker way. The high zero-order correlation between the two scales suggests that if one likes the parent one is caring for, then caregiving will be seen as positive; if one does not get along with the parent being cared for, then caregiving satisfaction will be low. If so, it is better to measure relationship quality directly rather than relying on a surrogate. None of the above studies that examined caregiving satisfaction included a measure of relationship quality in their analyses.

Is the Mental Health Inventory Also Redundant?

If the caregiving satisfaction scale is redundant, how about the Mental Health Inventory? It dropped out of the model when likelihood of nursing home placement was regressed on both it and perceived caregiving burden. While it did not appear needed in this particular case, the value of this scale for more general health considerations, both as a dependent and as an independent variable, has been demonstrated. It forecasts the use of future mental health services (Ware, Willard, Manning, Duan, Wells, and Newhouse, 1984), the use of future general medical care services (Manning, Newhouse, and Ware, 1982), and has shown to be associated with social support, stressful life events, and physical limitations (Williams, Ware, and Donald, 1981). It is also known to be somewhat lower for persons with chronic illness and substantially lower for persons diagnosed with depression (Cassileth, et al., 1984). Varying scores on the Mental Health Inventory can be interpreted more directly as a reflection of actual mental health than can any burden measure. Using a mental health scale helps answer the question of just what caregiving burden really means in a broader context. By itself a burden measure may not mean much -- many things in life are burdensome but uninteresting for extensive study or public policy. Showing that caregiving burden does impact mental health adds to the importance of adult caregiving studies.

Upset with Support a More Powerful Measure than Helpfulness

Confirming the work of Pagel, Erdly, and Becker (1987), measuring how upset caregivers were with persons in their support network had a more powerful effect on caregiving outcomes than did a comparable helpfulness measure. Asking about something expected but not received appears to yield stronger results than asking about varying positive levels of something being received. Their measure merits further use.

The particular design of the upset instrument used in this study may represent an improvement, however. Pagel, Erdly, and Becker first determined the support network by asking the subjects to list everyone (up to 15 people) who was important to them and whom they had seen over the past two weeks. Such a broad question results in a relatively long list for some subjects but leaves out persons who are expected to help but are not doing so. The procedure here determined the network by asking who was helping the caregiver and who was not but should have been. The result was a mean of 3.2 persons named compared with 5.8 in the Pagel, Erdly, and Becker study and included the recalcitrant relatives that would have been left out by their procedures. Limiting the response set to those included in this study appears to be an improvement. The instrument focuses on what is important to measure and avoids becoming tedious for both the interviewer and the subject.

Findings from the Path Model

As hypothesized, relationship quality, caregiving support upset, and caregiving tasks were associated with likelihood of nursing home placement indirectly through perceived caregiving burden, which was in-turn directly linked to the nursing home variable. Contrary to what was hypothesized, duty exerted a direct effect on likelihood of nursing home placement and had no relationship with perceived caregiving burden. Feeling obligated to care for the care-receiver, in other words, did not lessen or increase burden, but it did decrease the perceived likelihood that the care-receiver would eventually be placed in a nursing home.

As hypothesized, relationship quality had a positive association with duty, but, contrary to what was hypothesized, had no association with caregiving tasks. The wide range of scores on the relationship quality scale and its lack of any association with caregiving tasks support Jarret's (1985) observation that caring for frail parents by adult children is based upon mutual obligations and can take place in the absence of affection Some of the adult child caregivers in this study got along poorly with their parents, but caregiving went on anyway and did not appear to be reduced as a result of the poor relationship quality.

Relationship quality had been hypothesized to indirectly reduce the likelihood of nursing home placement by reducing perceived burden, but also indirectly increase the likelihood of nursing home placement by increasing caregiving tasks. Since the path between relationship quality and caregiving tasks was not retained in the model, relationship quality had a consistent indirect effect on the likelihood of nursing home placement. It increased duty which lessened the likelihood of nursing home placement and decreased both perceived caregiving burden and caregiving support upset, both of which increased the likelihood of nursing home placement.

The negative association between relationship quality and perceived caregiving burden (both directly and indirectly through caregiving support upset) supports the negative association between relationship quality and burden reported by Fengler and Goodrich (1979) and is the opposite to that reported by Cantor (1983). Several factors in the current study suggest that relationship quality is relatively stable during the course of caregiving. The scale itself consisted of items measuring both past and present relationship aspects, and these items were highly correlated. There was also no association between relationship quality and either caregiving tasks or length of caregiving. It seems as though one gets along well or poorly with one's parents, and such feelings do not to change very much as a result of caregiving. However, the mean relationship quality score obtained in the current study is eight points below the non-caregiver results reported by Walker and Thompson (1983) and three points below the caregiver results reported by Walker et al. (1990). If relationship quality is indeed relatively constant during caregiving, then why are the caregivers in this study scoring so much lower? Part of the answer is that in both of the Walker studies the subjects volunteered to talk about their relationships with their mothers and were required to secure the mothers' cooperation in order to take part. Adult children volunteering for such a study and required to secure the cooperation of their mothers probably get along better with their mothers than does the average adult child. Furthermore, demented care-receivers were excluded from the second study. Selection bias likely explains the higher Walker scores.

By having direct effects on three of the other variables and indirect effects on a fourth, relationship quality emerged as a more important variable in the revised model than originally hypothesized. It increased the sense of duty toward caring for a frail parent, lessened perceived caregiving burden and made problems with relatives presumably easier to bear. Through these three variables it indirectly reduced the perceived likelihood that the care-receiver would be placed in a nursing home.

Similar variation was noted on the duty scale. Some caregivers felt a strong sense of duty to provide care -- others did not. Duty to care appears to be partly a function of the relationship history between the individuals involved and partly the result of normative beliefs. When asked if in general adult children had an obligation to care for their parents when they became old and frail, 25% felt that the obligation depended upon the kind of relationship the parties had had in the past and on the particular situation for both parties at the time when caregiving was being considered. Several noted that competing obligations (such as to one's own children) might take precedence over caring for parents. Of those who felt that adult children did have a general obligation to care, 30% gave reciprocity as a reason, which again would be affected by relationship quality. Most of the other responses to the question, however, revolved around the existence of a general obligatory norm -- adult children should care for their parents because it is the right thing to do, is an integral part of the family, is prescribed by religious values, or because "I was brought up that way." Three of the caregivers had been raised with specific instructions that they had a duty to care for their mothers. In two cases the instructions had come from fathers who feared what would happen if they died before the mother did, while the third case involved other relatives telling the caregiver that she had a special obligation towards her mother because she (the mother) was one of the few family members to survive the Holocaust.

Comparing the two aspects of duty, specific aspects (obligations felt toward the parent being cared for which partly stem from relationship quality) appeared to have more of an impact on perceived likelihood of nursing home placement than did statements about general obligations of adult children toward their parents. But both aspects of duty appeared when caregivers were asked how obligated they felt.

Both duty and relationship quality had been hypothesized to have a direct relationship with caregiving tasks, but neither path proved to be significant. Even the zero-order correlation between relationship quality and tasks was virtually non-existent ($r = .03$). Duty, on the other hand, did have a significant zero-order correlation ($r = .21$, $p < .05$) with caregiving tasks but slipped just below significance when caregiving tasks was regressed on income and duty at the same time ($B = .18$, $p \leq .07$). It is possible, then, that a somewhat larger study could have shown that duty does cause a caregiver to do more while relationship quality does not, although the relationship involved may be a relatively modest one.

The two variables of income and care-receiver dementia were added to the model. Income indirectly affected perceived caregiving burden by decreasing the number of caregiving tasks performed. Several of the caregivers with higher incomes in this study had hired full-time help to reduce their own tasks. Higher income makes nearly all caregiving support services more readily available; and was also shown in this study to improve mental health.

Care-receiver dementia increased likelihood of nursing home placement, but had no relationship to any of the other major variables. Having a demented care-receiver does not appear to increase perceived caregiving burden, cause poorer caregiver mental health, reduce the relationship quality between the caregiver and the care-receiver, or cause caregivers to report greater upset with support received from other family members. Such non-relationships are puzzling. According to the research literature dementia should cause increased caregiver perceived burden and poorer mental health (Barusch and Spaid, 1989; Chenoweth and Spencer, 1986; Horowitz, 1985). The results obtained cannot be caused by the care-receiver's dementia being mild: most of the demented care-receivers had been diagnosed as having Alzheimers Disease, and many of the caregivers talked about the serious personality changes and memory loss that had occurred in these persons. One commented: "I no longer have my father living with me; just a strange old man who scares me sometimes." Several noted that other relatives had reduced contact as a result of the dementia. Lack of association with relationship quality may make sense in that some of the caregivers of demented care-receivers felt that their past relationship with the care-receiver carried over into the present and answered accordingly. But the failure of any relationship between care-receiver dementia and either perceived caregiving burden or caregiving support upset is surprising, unless the conditions of the non-demented care-receivers were so serious that they cancelled out the additional problems caused by those with dementia.

The direct association of care-receiver dementia with nursing home placement in the presence of the other variables does have implications for long-term care services. The main cause of senile dementia (Alzheimers Disease) is rapidly increasing, and may affect 40% of Americans 85 years old and older (Evans et al., 1989). As noted earlier, this oldest cohort represents the prime age group for nursing home placement and is itself growing rapidly. Thus the potential for increased nursing home use is certainly there, if caregivers of demented parents follow through on anticipated nursing home placement by actually placing their parents in nursing homes sooner than they otherwise would.

Directions for Future Research

The relationships found in this study for adult child caregivers need to be tested on spouse caregivers, who constitute the majority of primary caregivers for the frail elderly. It would be interesting to see if caregiving tasks, relationship quality, duty, and social support upset have the same relationships to each other, to perceived caregiving burden, and to likelihood of nursing home placement as they do for adult child caregivers. Some differences are likely. Spouses, after all, choose one another, whereas none of the adult children in this study selected his or her parents. Duty to care for a spouse should be stronger overall than duty to care for a parent, which may make nursing home placement more unlikely. Family conflict may be less intense for spouse caregivers; they will already be living together and may not expect as much caregiving help from others. By the same argument perceived burden would likely be lower, but Cantor (1983) reports that spouse caregivers reported higher levels of perceived burden than did adult child caregivers. Her study did not control for caregiving tasks, and it is apparent that the spouse caregivers were doing more personal care for their frail spouses than were the adult children for their frail parents. Spouse - child caregiving comparisons are also compounded by the fact that spouse caregivers are much older and hence have more health problems themselves and fewer financial resources than do child caregivers. Applying the same analysis techniques used in the current study to examine spouse caregivers would help clarify the reasons for any differences observed.

It would also be useful to study conflict with relatives using a longitudinal research design. Do such conflicts start quickly in caregiving or do they develop later? How long do such conflicts continue? How do the parties involved try to resolve them? How successful are they at such resolution? Do other family members step in to fill the breach? Does it help to forewarn caregivers? All sorts of possibilities emerge. If conflict with other family members is really as common as reported in the current study, more research is needed to understand it.

More could be done to clarify the issues raised about the relative importance of relationship quality and how stable this concept really is. The caregivers in this study implied that relationship quality was relatively stable over time, yet their scores on the relationship quality scale were lower than for non-caregiving women. Was the comparison group not really typical of adult child-parent relationships or does relationship quality decrease early on in caregiving? The Walker-Thompson scale also needs some improvements to facilitate its use with caregivers who have demented care-receivers. It is not easy to decide whether to agree or disagree with an item like "We feel like we are part of a team" when the care-receiver is so demented that he/she no longer recognizes you. The obvious response would be to disagree with the statement, but some caregivers were reluctant to do so when they felt that they used to be close to the care-receiver before the dementia began. The real dilemma is how strongly past relationship quality caries over to the present when such drastic personality changes occur and whether a relationship quality scale should try to take any possible disparities into account. One possible solution would be to design two scales to measure past and present relationship quality and compare the results.

The relationship between likelihood of nursing home placement and actual placement needs to be examined. It is one thing to think about institutionalizing a parent but another thing to do it. The results reported here would be strengthened by a finding that caregivers generally follow through on placement when they consider it more likely.

Finally, it would be interesting to compare caregivers who were either pressured from others to initiate care or who had to suddenly take on the caregiving with those who planned for it some time ahead and did not feel pressured. Data were not collected in this study on those who had begun caregiving without planning for it, but several caregivers mentioned the point in passing and how stressful it had been. One had started when she received a call from an uncle that her alcoholic mother was sitting out on a sidewalk after having been evicted from her apartment; another found her mother nearly starving from poor care by a sister, while a third suddenly discovered the financial affairs of her demented father in complete disarray and realized he could no longer live alone. To this group could also be added those who were pressured by the care-receiver to take them in. Several caregivers indicated that they had felt pressured by their parent, such as one who said that her father threatened to commit suicide if she did not let him move in with her. Planning ahead for caregiving and initiating it without undue pressure may result in less burden than having it thrust upon one suddenly or having it occur under duress.

Conclusion

This study has shown how relationship quality, duty, caregiver support upset, and caregiving tasks are related to caregiver perceived burden and likelihood of nursing home placement. With the exception of duty, all are related to likelihood of nursing home placement indirectly through their relationships with caregiver perceived burden. Caregiver support upset and caregiving tasks increase caregiver perceived burden while relationship quality decreases it. Duty decreases the likelihood of nursing home placement while care-receiver dementia increases it. Relationship quality also has a positive relationship with duty and a negative relationship with caregiver support upset. Caregiver income reduces caregiving tasks.

Caregiving satisfaction was shown to be essentially redundant, with relationship quality doing a better job of measuring the same underlying construct. As measured by the Mental Health Inventory, caregiver well-being was shown to have no independent association with perceived likelihood of nursing home placement when caregiver perceived burden was taken into account. Nevertheless, the relatively low scores on the Mental Health Inventory recorded by the caregivers in this study and the strong positive association between caregiver perceived burden and mental health demonstrate that caring for a frail parent is indeed burdensome and has implications for the health care delivery system.

The data in this study also indicate that family conflict for adult child caregivers is relatively frequent and has an impact on mental health, perceived burden, relationship quality, likelihood of nursing home placement, and feelings about how the caregiver would want to be treated should he/she become disabled. Anticipating such conflict and learning how to deal with it might improve caregiving outcomes for both caregivers and care-receivers.

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Appendix 1

Recruitment Materials

Informed Consent

Sample Subject Recruitment Letter

Dear

Would you like to take part in a University of Washington study to help develop better long-term services? Mr. William Strawbridge and his assistant, Mrs. Laura Hebert, are here at the [site] to study the problems and benefits of providing care in home settings. They hope to learn how to design better services to assist persons like yourself who are caring for elderly relatives and would like to have your ideas. Their study is also funded by the Veterans Administration, so your opinions could affect national policy.

In order to take part you need to be helping care for a parent or inlaw who is not in a nursing home. If you agree to participate, Mr. Strawbridge or Mrs. Hebert will come to your home or to a place convenient to you for an hour's interview.

Taking part in this study is entirely voluntary. Whether you decide to do so or not will have no effect on any service you receive from us, nor on any funding that you may receive. All of your statements to them will be kept strictly confidential.

If you are interested in learning more about this study, please fill in the enclosed card and mail it in the self-addressed envelope. Thank you for taking the time to read our letter.

Sincerely,

[Site Staff Name]
[Title]

Sample Subject Return Card

[Participating Site Name]

YES, I am interested in learning more about the caregiving study. Please have Mr. Strawbridge or Ms. Hebert give me a call.

My Name: ____

Address: ____

____

Telephone: ____________________________

Best Times to Call: ____

UNIVERSITY OF WASHINGTON
CONSENT FORM

Social Aspects of Caregiving

Investigator:

William J. Strawbridge, M.A., MPH
Doctoral Candidate
Department of Sociology DK-40
University of Washington
Seattle, Washington 98195
(206) 523-6352

Purpose and Benefits

The purpose of this study is to learn how various social factors affect the experience of adults caring for parents or in-laws in home settings. I am doing this study as part of my doctoral program in the Department of Sociology at the University of Washington. The information gained from your participation will help identify long-term care services to assist persons like yourself in caring for someone.

Procedures

The study involves one interview with you. The interview takes about an hour and includes questions about you and what sorts of caregiving activities you do, the kind of relationship you have with the person you are caring for, how caregiving has impacted your life, how you feel about the help you receive from those you feel should be helping you, and how you feel about other services to help you provide better care. Specifically, the questions include:

Items about how well you get along with the person you are caring for, such as how close you feel to them now and whether they did things for you in the past. Items about whether you feel a sense of obligation to provide care, such as whether you feel you should be willing to adjust some of the things you may want for your own family in order to help provide care, and items about satisfactions that you may or may not have as a result of caregiving.

Items concerning how you felt over the past month, such as how often you woke up feeling fresh and rested or how often you felt downhearted and blue. Items about whether you have thought at all about eventually having the person you are taking care of cared for in a nursing home. Examples are feeling that if things get any harder you are going to have to consider nursing home care or that others tell you it might be better for everyone if the person you care for were in a nursing home.

Items about the impact caregiving has had on your own life, such as whether you feel you do not have enough time for yourself or whether you worry about what might happen in the future. Items about persons who may be helping you provide care, such as how satisfying their assistance is to you or how upsetting to you they are.

Additional items about your feelings and needs, such as services you feel might be helpful and what your biggest problem and greatest satisfaction are in caregiving.

If it is all right with you, I would like to tape our interview. That way I can concentrate on what you are saying and write down any longer answers that you give later. You are free to review the tape if you wish. You are also free to say that you do not want me to tape the interview, in which case we will simply proceed without taping.

Throughout the interview please feel free to answer only those questions that you want to answer. If you get tired and want to take a break, that is fine too.

Risks

There are no known physical risks in taking this interview. Some persons feel temporary sadness in talking about the person they are caring for or about their own feelings. Remember, though, that you can refuse to answer any question I ask.

Other Information

The information you provide me will be kept confidential. Only my research advisor and I will have access to it. Everything I collect from you will be identified only by a code number, so that no names will appear on the data collection forms. The only place your name will appear is on this consent form, which will then be filed separately from your responses to the questions. When my report is written, only summary results will be reported. Should I want to use a specific statement to illustrate a point, I will camouflage your remarks so that it will be impossible to know who actually said what. The information collected in this study will be retained for no more than ten years.

Your participation is this study is voluntary. You are free to withdraw from the study at any time without penalty or effect on any services or funding that you may be receiving. Do you have any questions?

DATE

SIGNATURE OF INVESTIGATOR

PARTICIPANT'S STATEMENT

The study described above has been explained to me and I have had an opportunity to ask questions. I understand that future questions I may have about the research or my rights will be answered by Mr. Strawbridge. I voluntarily consent to participate.

DATE

SIGNATURE OF PARTICIPANT

Copy to: Participant

Appendix 2

Questionnaire

Face Sheet

1. Caregiver Code # ______

2. Referral Site # ______

3. Date of Interview ______/______/______

4. Interviewer: ______________________________

5. Interview Setting:	Caregiver's residence	1
	Care-receiver's residence	2
	Other (Specify) ______________________	3
6. Race/ethnicity of caregiver. (CODE WITHOUT ASKING).	White	1
	Black	2
	Asian	3
	Latino/Hispanic	4
	Other (Specify) ______________________	5

COMMENTS

Caregiver Code #____

Section A - Background Data

FILL IN PAGES 2-3 FROM SCREENING QUESTIONS.

A-1. Sex of Caregiver.	Male 1 Female 2
A-2. Age of care-receiver.	____ Years
A-3. Relationship of care-receiver to caregiver.	Mother 1 Father 2 Mother-in-law 3 Father-in-law 4
A-4. ACTIVITIES OF DAILY LIVING:	
Number of IADLs caregiver provides help for or does for care-receiver.	____ #IADLs
Number of ADLs caregiver provides help for or does for care-receiver.	____ #ADLs
A-5 Approximate number of hours per week caregiver spends providing care for care-receiver. Include help with personal care (such as bathing, eating, or dressing) and helping in any other way (such as shopping, housekeeping, transportation, taking medications, or preparing meals.) If "full time" and unable to estimate number of hours, code 998.	____ Hours (Full time=998) (Unknown=999)
A-6. What major medical or health problems does care-receiver have care? ____________________ ____________________ ____________________	____ Code

Caregiver Code #______

A-7. Who does care-receiver live with? 1. With caregiver.(SKIP NEXT QUESTION) 2. By himself/herself. 3. With spouse. 4. Other (explain). ____	______ Code
A-8. About how many miles does caregiver live from care-receiver? ______________ miles.	______ Miles
A-9. Is caregiver the one who is most responsible for taking care of care-receiver or is there someone else who provides more care than caregiver? If there is someone else, who is it? 1. Subject is primary caregiver. 2. Care-receiver's spouse is primary caregiver. 3. Care-receiver's son is primary caregiver. 4. Care-receiver's sister is primary caregiver. 5. Caregiver's spouse is primary caregiver. 6. Responsibility is equally shared. 7. Other (EXPLAIN) ____	______ Code

Caregiver Code #______

BEGIN INTERVIEW HERE.

Information about your background sometimes can be helpful in understanding how you deal with caregiving, so first I am first going to ask you some questions about yourself.

A-10. What is your date of birth? ______________ Month Day Year	Age (yrs) ________
A-11. Are you currently married, widowed, divorced, separated, or have you never been married?	married 1 widowed 2 divorced 3 separated 4 never married 5 "partnered" 6
A-12. How many children do you have? IF "NONE" SKIP TO A-14.	Number ________
A-13. How many of them presently live with you?	Number ________
A-14. How many brothers do you have?	Number ________
A-15. How many sisters do you have?	Number ________
A-16. What is the highest grade or level you reached in school? ______________________________ 1. Did not graduate from high school. 2. High school graduate or equivalent. 3. Some college. 4. College degree. 5. Graduate school degree.	________ Code

Caregiver Code #______

A-17. In general, would you say that your health in the last month has been excellent, very good, good, fair, or poor?	excellent 1 very good 2 good 3 fair 4 poor 5
A-18. How would you say your health compares with other persons your age? Would you say your health is better than, about the same as, or worse than others your age?	better 1 about the same 2 worse 3
A-19. Are you presently employed? (IF NO, SKIP TO A-21)	Yes 1 No 2
A-20. (IF YES) About how many hours per week do you work?	______ Hours (Not employed=99)
A-21. (IF YES) What sort of work do you do? ______________________________ (describe)	______ Code (Not employed=99)
A-22. Have you reduced or adjusted the number of hours you work now or used to work as a result of your caring for your (relationship)? (IF YES, REDUCED) By about how many hours per week?	Yes, reduced 1 Yes, adjusted 2 No, neither 3 ______ Hours (NA=99)
A-23. When we talk about your (relationship), how do you want me to refer to (him/her)? Should I use his/her name or just say your (relationship) or something else? ______________________________ USE THIS NAME FOR CARE-RECEIVER FROM NOW ON	

Caregiver Code #______

A-24. About how many years have you been providing care for (care-receiver)?		______ Years
A-25. Is (care-receiver) presently attending an adult day health program?	Yes No	1 2
A-26. Does (care-receiver) presently have any care provided by a visiting nurse service or other care provided at home?	Yes No	1 2
A-27. Are you now using respite care services?	Yes No	1 2
A-28. Are you a member of a caregiver support group?	Yes No	1 2

GO TO NEXT PAGE

Caregiver Code #______

A-29. Besides persons who are paid, like doctors and nurses, who, if anyone, helps you take care of (care-receiver)? For each person please tell me their first name, what their relationship is to you, what he or she does to help you, and about how many hours per week he or she spends providing such help. Include family members, friends, neighbors, or any other person who is not paid to help you.

(AFTER EACH NAME, PROBE "ANYONE ELSE?")

First Name	Rel. Code	Help Provided	Hours/wk
First Name	Rel. Code	Help Provided	Hours/wk
First Name	Rel. Code	Help Provided	Hours/wk
First Name	Rel. Code	Help Provided	Hours/wk
First Name	Rel. Code	Help Provided	Hours/wk
First Name	Rel. Code	Help Provided	Hours/wk

Relationship Codes

Parent	1	Child	4	Other Relative	7	Volunteer	10
Spouse	2	Uncle/Aunt	5	Friend	8	Other (specify)	11
Sibling	3	Cousin	6	Neighbor	9		

Caregiver Code #______

B. Caregiving Tasks

Now I am going to read you some statements about caregiving activities that you may or may not be doing now for (care-receiver). Here is a card (HAND CARD A) to help you remember the different responses. For each item please tell me if you do it never, rarely, several times a month, every week, several times a week, or daily.

	Never	Rarely	Several times a month	Every week	Several times a week	Every Day
B-1. I help (care-receiver) with eating (his/her) food.	1	2	3	4	5	6
B-2. I help (care-receiver) with his/her personal care (such as dressing, bathing, hair care, or teeth care.	1	2	3	4	5	6
B-3. I help (care-receiver) use the toilet, bedpan, or commode.	1	2	3	4	5	6
B-4. I help (care-receiver) walk across the room.	1	2	3	4	5	6
B-5. I help (care-receiver) get in and out of bed, chair, or couch.	1	2	3	4	5	6
B-6. I plan (care-receiver's) meals.	1	2	3	4	5	6
B-7. I prepare (care-receiver's) meals.	1	2	3	4	5	6
B-8. I take care of (care-receiver's) banking, paying bills, or other financial matters.	1	2	3	4	5	6
B-9. I do shopping, appointments, or run errands for (care-receiver).	1	2	3	4	5	6

Caregiver Code #______

	Never	Rarely	Several times a month	Every week	Several times a week	Every Day
B-10. I help (care-receiver) with writing letters, phone calls, or other personal communications.	1	2	3	4	5	6
B-11. I help (care-receiver) with laundry or other household chores.	1	2	3	4	5	6
B-12. I provide transportation for (care-receiver) in getting from home to other places.	1	2	3	4	5	6
B-13. I help (care-receiver) take his/her medications and/or prescribed treatments.	1	2	3	4	5	6
B-14. I contact the doctor about (care-receiver's) medications and/or treatment needs.	1	2	3	4	5	6
B-15. I check on (care-receiver) during the night.	1	2	3	4	5	6

Caregiver Code #______

C. Relationship Quality

Now I am going to read some statements to you about how you and your (father/ mother/ father-in-law/ mother-in-law) get along with one another. Talking about someone close to you is often difficult, so some of these questions may be hard to answer. However, it is important to be as honest and accurate as possible. No one is trying to judge you or your feelings about (care-receiver). As I read each statement I would like you to tell me if you agree or disagree with it. After you decide if you agree or disagree, I will then ask you if you moderately or strongly agree or disagree. Except where indicated, these statements refer to how you feel about your relationship with (care-receiver) at the present time.

Let's begin with (READ C-1). Do you agree or disagree? Moderately or strongly?

	AGREE		**DISAGREE**		
	Strongly	**Moderately**	**Moderately**	**Strongly**	**MS/ DK/NA**
C-1. (Care-receiver) and I want to spend time together.	1	2	3	4	9
C-2. (Care-receiver) shows that (he/she) loves me.	1	2	3	4	9
C-3. We're honest with one another.	1	2	3	4	9
C-4. We can accept each other's criticism of our faults and mistakes.	1	2	3	4	9
C-5. We like each other.	1	2	3	4	9
C-6. We respect each other.	1	2	3	4	9
C-7. Our lives are better because of our relationship.	1	2	3	4	9
C-8. We enjoy our relationship.	1	2	3	4	9

Caregiver Code #______

	AGREE		DISAGREE		
	Strongly	Moderately	Moderately	Strongly	MS/ DK/NA
C-9. (Care-receiver) cares about the way I feel.	1	2	3	4	9
C-10. We feel like we are a unit.	1	2	3	4	9
C-11. There is a great amount of unselfishness in our relationship.	1	2	3	4	9
C-12. (Care-receiver) thinks of my best interest.	1	2	3	4	9
C-13. I am lucky to have (care-receiver) in my life at the present time.	1	2	3	4	9
C-14. (Care-receiver) makes me feel better.	1	2	3	4	9
C-15. (Care-receiver) is important to me.	1	2	3	4	9
C-16. We love each other.	1	2	3	4	9
C-17. I feel sure of our relationship.	1	2	3	4	9
C-18. (Care-receiver) and I share similar values about what is important in life.	1	2	3	4	9
C-19. (Care-receiver) has given me good advice over the years.	1	2	3	4	9
C-20. (Care-receiver) has given me emotional support when I needed it.	1	2	3	4	9

Caregiver Code #______

	AGREE		DISAGREE		
	Strongly	Moderately	Moderately	Strongly	MS/ DK/NA
C-21. (Care-receiver) has made some real sacrifices for me in the past.	1	2	3	4	9
C-22. (Care-receiver) has always been there when I needed him/her.	1	2	3	4	9

Caregiver Code #______

D. Sense of Duty

Now I am going to read some statements that other people have made about how obligated they do or do not feel about caring for a (parent, parent-in-law). Again, as I read each statement I would like you to tell me if you agree or disagree with it. After you decide if you agree or disagree I will then ask you if you moderately or strongly agree or disagree.

Let's begin with (READ D-1). Do you agree or disagree? Moderately or strongly?

Begin each statement with "Because (care-receiver) (he/she) is my (relationship) I feel I should. . ."

	AGREE		DISAGREE		
	Strongly	Moderately	Moderately	Strongly	MS/ DK/NA
D-1. . . . give (him/her) emotional support even when it is not always convenient.	1	2	3	4	9
D-2. . . . be willing to give (him/her) financial help when necessary.	1	2	3	4	9
D-3. . . . help take care of (him/her) now that (he/she) is old and frail.	1	2	3	4	9
D-4. . . . be willing to adjust my work schedule in order to care for (him/her).	1	2	3	4	9
D-5. . . . be willing to share my home with (him/her).	1	2	3	4	9
D-6. . . . be willing to sacrifice things I want for my own family or myself in order to care for (him/her).	1	2	3	4	9
D-7. . . . be willing to make major changes in my life in order to care for (him/her).	1	2	3	4	9

Caregiver Code #______

Begin each statement with "Because (care-receiver) (he/she) is my (relationship) I feel I should. . ."

	AGREE		DISAGREE		
	Strongly	**Moderately**	**Moderately**	**Strongly**	**MS/DK/NA**
D-8. . . . be willing to do whatever it takes to keep caring for (him/her) at home.	1	2	3	4	9
- - Read remaining questions as is without introductory statement - -					
D-9. Family values are very important to me.	1	2	3	4	9
D-10. I would feel guilty if I were not caring for (care-receiver).	1	2	3	4	9
D-11. I feel that (care-receiver) should try to rely more on (his/her) own resources rather than expecting me to help so much.	1	2	3	4	9
D-12. I feel it would be better to develop more community resources to care for older persons like my (relationship) rather than leaving it to adult children like me to provide care.	1	2	3	4	9
D-13. I feel that persons with family or job responsibilities should not be expected to provide care for their aging parents/in-laws.	1	2	3	4	9

Caregiver Code #______

E. Caregiving Satisfactions

Now I am going to read some statements that other people have made about satisfactions that they found in caring for someone. Some, all, or none of these statements may apply to you. Again, as I read each statement I would like you to tell me if you agree or disagree with it. After you decide if you agree or disagree I will then ask you if you moderately or strongly agree or disagree.

Let's begin with (READ E-1). Do you agree or disagree? Moderately or strongly?

	AGREE		DISAGREE		
	Strongly	Moderately	Moderately	Strongly	MS/ DK/NA
E-1. Caring for (care-receiver) gives my self-esteem a boost.	1	2	3	4	9
E-2. It helps to know that I am doing my best in caring for (care-receiver).	1	2	3	4	9
E-3. Caring for (care-receiver) helps keep (him/her) from getting sicker than (he/she) otherwise would.	1	2	3	4	9
E-4. By providing care I am living up to my religious or moral principles.	1	2	3	4	9
E-5. I have grown closer to (care-receiver) as a result of caring for (him/her).	1	2	3	4	9
E-6. I feel better about myself for being willing to care for (care-receiver).	1	2	3	4	9
E-7. I feel that there is more purpose and meaning in my life as a result of caring for (care-receiver).	1	2	3	4	9

Caregiver Code #______ 16

	AGREE Strongly	 Moderately	DISAGREE Moderately	 Strongly	MS/ DK/NA
E-8. Caring for (care-receiver) has helped me realize that I can do things I never knew before that I could do.	1	2	3	4	9
E-9. I feel useful because I know I am helping someone.	1	2	3	4	9
E-10. Caring for (care-receiver) has brought some of our family closer together.	1	2	3	4	9
E-11. Caring for (care-receiver) has taught me to deal better with my emotions.	1	2	3	4	9
E-12. Caring for (care-receiver) has taught me to distinguish the important things in life from the not-so-important.	1	2	3	4	9
E-13. I have been able to use special skills that I have to help (care-receiver) continue to do the things that (he/she) enjoys doing.	1	2	3	4	9
E-14. Caring for (care-receiver) has taught me some important things about myself.	1	2	3	4	9
E-15. Caring for (care-receiver) gives me small but important uplifts now and then.	1	2	3	4	9

Caregiver Code #______ 17

F. Perceived Likelihood of Nursing Home Placement

Some caregivers like yourself think that eventually the person they are caring for will have to be cared for in a nursing home, while others have not thought much about it. I am going to read some statements about eventual nursing home placement to you. Again, as I read each statement I would like you to tell me if you agree or disagree with it. After you decide if you agree or disagree I will then ask you if you moderately or strongly agree or disagree.

Let's begin with (READ F-1). Do you agree or disagree? Moderately or strongly?

	AGREE		DISAGREE		
	Strongly	Moderately	Moderately	Strongly	MS/ DK/NA
F-1. Other people tell me it might be better for everyone if (care-receiver) were being cared for in a nursing home.	1	2	3	4	9
F-2. If things get any harder, I may have to consider placing (care-receiver) in a nursing home.	1	2	3	4	9
F-3. The way things are right now, I sometimes feel that (care-receiver) would be better off being cared for in a nursing home.	1	2	3	4	9
F-4. I've reached the point where I just cannot provide any more care for (care-receiver). I am thinking about nursing home placement.	1	2	3	4	9
F-5. No matter how difficult things become I do not plan on allowing (care-receiver) to be cared for in a nursing home.	1	2	3	4	9

Caregiver Code #______ 18

G. Caregiver Perceived Burden of Altered Life-Style

Now I am going to read you some statements about problems or concerns that some other persons taking care of someone have said they have as a result of their caregiving. These problems or concerns may or may not apply to you.

Here is a card to help you remember the different responses (HAND CARD B). For each item please tell me if it is "never a problem or concern" for you, "sometimes a problem or concern for you," "often a problem or concern for you," or "always a problem or concern for you."

	Never A Problem Or Concern	**Sometimes A Problem Or Concern**	**Often A Problem Or Concern**	**Always A Problem Or Concern**	**RA/ NA**
G-1. My social life has suffered since I started caring for (care-receive).	1	2	3	4	9
G-2. I no longer feel I have enough time for myself.	1	2	3	4	9
G-3. I now feel so tied down.	1	2	3	4	9
G-4. I now worry about (care-receiver) all the time.	1	2	3	4	9
G-5. I do not have enough privacy any more.	1	2	3	4	9
G-6. I now feel isolated and alone.	1	2	3	4	9
G-7. I now find it hard to meet (care-receiver's) demands.	1	2	3	4	9
(SKIP IF SUBJECT NOT MARRIED)					
G-8. Tensions with my (husband/ wife) have increased.	1	2	3	4	9

Caregiver Code #______ 19

	Never A Problem Or Concern	Sometimes A Problem Or Concern	Often A Problem Or Concern	Always A Problem Or Concern	RA NA
G-9. Caring for (care-receiver) has increased tensions with some other members of my family.	1	2	3	4	9
G-10. I just can no longer do the things that need to get done.	1	2	3	4	9
G-11. (Care-receiver's) needs now determine my time.	1	2	3	4	9
G-12. I now feel embarrassed when guests are around.	1	2	3	4	9
G-13. My emotional or physical health has suffered.	1	2	3	4	9
G-14. It bothers me that it is so hard to plan ahead now.	1	2	3	4	9
G-15. I feel torn between trying to deal with (care-receiver's) needs and those of other family members or friends.	1	2	3	4	9
G-16. It is now so hard for me to keep active in other things.	1	2	3	4	9
G-17. I am now unable to give as much attention to my outside work or other activities as I would like.	1	2	3	4	9

Caregiver Code #______

	Never A Problem Or Concern	Sometimes A Problem Or Concern	Often A Problem Or Concern	Always A Problem Or Concern	RA NA
G-18. (Care-receiver's) needs are always on my mind.	1	2	3	4	9
G-19. I now worry about what will happen in the future.	1	2	3	4	9
G-20. I now worry about what will happen if a sudden crisis in (care-receiver's) health or condition occurs.	1	2	3	4	9
G-21. Friends and relatives just no longer come by as often as they used to.	1	2	3	4	9
G-22. I worry about the cost of (care-receiver's) care.	1	2	3	4	9

Caregiver Code #______

H. Social Network Upset

Now I am going to ask you some more questions about persons who may or may not be helping you in caring for (care-receiver). As before, they can be family members, friends, neighbors, or acquaintances, anyone who is not paid to help you. In no way will I contact any of these people, nor will any of them know what you have said about them here.

A. A while ago you said that (READ FROM HELPER LIST IN QUESTION A-28) help you care for (care-receiver.) I am now going to transfer their names to this part of the questionnaire. (RECORD NAMES AND RELATIONSHIP CODES ON NEXT PAGE)

B. Are there any family members, friends, neighbors, or others you feel <u>should</u> be helping you more in caring for (care-receiver) that you haven't already named? IF YES: please give me their names as well. (RECORD NAMES ON NEXT PAGE). (AFTER EACH NAME PROBE "ANYONE ELSE?)

C. Other than those you have already named, please give me the names of anyone you talk with about personal worries or concerns connected with your caring for (care-receiver). (IF YES), please give me their first names. (RECORD NAMES ON NEXT PAGE) (AFTER EACH NAME PROBE "ANYONE ELSE?)

Caregiver Code #______

H-1 **PERSON** Name	H-2 How Is **PER-? SON** Related To You?
1.	CODE
2.	CODE
3.	CODE
4.	CODE
5.	CODE
6.	CODE
7.	CODE
8.	CODE

RELATIONSHIP CODES

Parent	1
Spouse	2
Sibling	3
Child	4
Uncle/Aunt	5
Cousin	6
Other relative	7
Friend	8
Neighbor	9
Volunteer	10
Other (specify)	11

For each person you named, I am going to ask you how helpful and how upsetting to you he or she is in several ways. Here are two cards to help you with the responses (HAND CARDS C AND D). Let's begin with (FIRST NAME):

GO TO NEXT PAGE. WRITE FIRST NAME AT TOP OF PAGE.

If subject names more than six persons, ask following questions only of first six named, starting with those in category B, then A, and then C.

Caregiver Code #______ PERSON Name __________ 23-29

H-3	H-4	H-5	H-6
Does PERSON help you with caregiving tasks? YES 1 NO 2 (Go to H-6)	How helpful is PERSON when providing you with this assistance? not helpful 1 slightly helpful 2 somewhat helpful 3 very helpful 4	How upsetting is it to you when PERSON provides you with this assistance? not upsetting 1 slightly upsetting 2 somewhat upsetting 3 very upsetting 4	How upsetting is it to you that PERSON does NOT provide you with this assistance? not upsetting 1 slightly upsetting 2 somewhat upsetting 3 very upsetting 4
Does PERSON give you advice, suggestions, or information in an effort to help you think through your problems? YES 1 NO 2 (Go to H-6)	How helpful is PERSON when (he/she) provides this kind of assistance? not helpful 1 slightly helpful 2 somewhat helpful 3 very helpful 4	How upsetting is it to you when PERSON provides this kind of assistance? not upsetting 1 slightly upsetting 2 somewhat upsetting 3 very upsetting 4	How upsetting is it to you that PERSON does NOT provide this kind of assistance? not upsetting 1 slightly upsetting 2 somewhat upsetting 3 very upsetting 4
Do you share activities with PERSON such as recreation, shopping, or conversation? YES 1 NO 2 (Go to H-6)	How helpful is PERSON to be with when you share these activities? not helpful 1 slightly helpful 2 somewhat helpful 3 very helpful 4	How upsetting is it to you when you share these activities with PERSON? not upsetting 1 slightly upsetting 2 somewhat upsetting 3 very upsetting 4	How upsetting is it to you that PERSON is not someone with whom you share these activities? not upsetting 1 slightly upsetting 2 somewhat upsetting 3 very upsetting 4
Does PERSON provide you with emotional support, such as sympathy, caring, understanding and reassurance? YES 1 NO 2 (Go to H-6)	How helpful is PERSON when providing you with emotional support? not helpful 1 slightly helpful 2 somewhat helpful 3 very helpful 4	How upsetting is it to you when PERSON provides you with emotional support? not upsetting 1 slightly upsetting 2 somewhat upsetting 3 very upsetting 4	How upsetting is it to you that PERSON does not provide you with emotional support? not upsetting 1 slightly upsetting 2 somewhat upsetting 3 very upsetting 4
Is PERSON someone to whom you can frankly reveal your feelings, thoughts, and concerns? YES 1 NO 2 (Go to H-6)	How helpful is PERSON when you reveal your feelings? not helpful 1 slightly helpful 2 somewhat helpful 3 very helpful 4	How upsetting is it to you when you reveal your feelings to PERSON? not upsetting 1 slightly upsetting 2 somewhat upsetting 3 very upsetting 4	How upsetting is it to you that PERSON is NOT someone to whom you can reveal your feelings? not upsetting 1 slightly upsetting 2 somewhat upsetting 3 very upsetting 4

Caregiver Code #______

I. Mental Health Inventory

These next questions are about how you have been feeling, and how things have been with you during the past month.

HAND CARD E. Please look at this card and tell me:

(USE "WOULD YOU SAY" PHRASE AFTER EACH QUESTION UNTIL SUBJECT RESPONDS WITHOUT BEING PROMPTED.)

	Always	Very Often	Fairly Often	Some times	Almost Never	Never
I-1. During the past month, how often have you been happy, satisfied, or pleased with your personal life? Would you say:	1	2	3	4	5	6
I-2. How much of the time have you felt lonely during the past month? Would you say:	1	2	3	4	5	6
I-3. How often did you become nervous or jumpy when faced with excitement or unexpected situations during the past month? Would you say:	1	2	3	4	5	6
I-4. During the past month, how much of the time have you felt that the future looked hopeful and promising?	1	2	3	4	5	6
I-5. How much of the time has your daily life been full of things that were interesting to you?	1	2	3	4	5	6
I-6. During the past month, how much of the time did you feel relaxed and free of tension?	1	2	3	4	5	6
I-7. How much of the time have you generally enjoyed the things you do?	1	2	3	4	5	6

Caregiver Code #______ 30

	Always	Very Often	Fairly Often	Some times	Almost Never	Never
I-8. How often have you wondered if you were losing your mind, your memory, or losing control over the way you act, talk, think, or feel?	1	2	3	4	5	6
I-9. How often did you feel depressed during the past month?	1	2	3	4	5	6
I-10. How much of the time have you felt loved and wanted?	1	2	3	4	5	6
I-11. During the past month, how much of the time have you been a very nervous person?	1	2	3	4	5	6
I-12. When you got up in the morning, about how often did you expect to have an interesting day?	1	2	3	4	5	6
I-13. How much of the time have you felt tense or "high-strung"?	1	2	3	4	5	6
I-14. During the past month, how often have you been in firm control of your behavior, thoughts, emotions, and feelings?	1	2	3	4	5	6
I-15. How often did your hands shake when you tried to do something?	1	2	3	4	5	6
I-16. How often did you feel that you had nothing positive to look forward to?	1	2	3	4	5	6
I-17. How much of the time have you felt calm and peaceful during the past month?	1	2	3	4	5	6

Caregiver Code #______

31

	Always	Very Often	Fairly Often	Some times	Almost Never	Never
I-18. How much of the time have you felt emotionally stable?	1	2	3	4	5	6
I-19. How much of the time have you felt downhearted and blue?	1	2	3	4	5	6
I-20. During the past month, how often have you felt like crying?	1	2	3	4	5	6
I-21. How often did you feel that others would be better off if you were dead?	1	2	3	4	5	6
I-22. How much of the time were you able to relax without difficulty?	1	2	3	4	5	6
I-23. How much of the time did you feel that your love relationships (loving and being loved) were full and complete?	1	2	3	4	5	6
I-24. During the past month, how often did you feel that nothing turned out for you the way you wanted it to?	1	2	3	4	5	6
I-25. How often have you been bothered by nervousness, or your "nerves"?	1	2	3	4	5	6
I-26. How often, during the past month, did you think about taking your own life?	1	2	3	4	5	6
I-27. How much of the time has living been a wonderful adventure for you?	1	2	3	4	5	6
I-28. How often have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6

Caregiver Code #______ 32

	Always	Very Often	Fairly Often	Some times	Almost Never	Never
I-29. During the past month, how much of the time have you felt restless, fidgety, or impatient?	1	2	3	4	5	6
I-30. How much of the time have you been moody or brooded about things?	1	2	3	4	5	6
I-31. How much of the time have you felt cheerful and light-hearted?	1	2	3	4	5	6
I-32. How often did you get rattled, upset, or flustered during the past month?	1	2	3	4	5	6
I-33. How often have you been anxious or worried?	1	2	3	4	5	6
I-34. How often were you a happy person?	1	2	3	4	5	6
I-35. During the past month, how often did you find yourself having difficulty trying to calm down?	1	2	3	4	5	6
I-36. How much of the time have you been in low or very low spirits?	1	2	3	4	5	6
I-37. How often have you been waking up feeling fresh and rested?	1	2	3	4	5	6
I-38. How often have you been under, or felt you were under any strain, stress, or pressure during the past month?	1	2	3	4	5	6

Caregiver Code #______

J. Open-Ended Questions

EXPLAIN THAT YOU ARE TURNING ON THE TAPE RECORDER NOW. MAKE NOTES OF MAJOR POINTS MADE. IF TAPE RECORDER IS NOT USED, MAKE MORE DETAILED NOTES.

1. What is the greatest burden, difficulty, or problem you have in caring for (care-receiver)?

2. What is the greatest satisfaction or least burden you have experienced in caring for (care-receiver)?

3. Do you feel any pressure from others around you to care for (care-receiver)?
   (IF YES) Who is giving you such pressure?

   (IF YES) How (does/do) (person(s) named) pressure you?

   (IF YES) How have you dealt with such pressure?

Caregiver Code #______ 34

4. Should this community have services or facilities available to help you care for (care-receiver)? IF YES, what services or facilities should be provided?

5. Do you feel that adults should be willing to take care of their parents or in-laws when they become old and frail? Why do you feel as you do?

6. What if anything, has caring for (care-receiver) taught you about how you might want to be taken care of if you were in a similar situation?

Caregiver Code #______

7. (IF APPROPRIATE). Finally, I am interested in what you said when we were talking about how upsetting some persons are to you. You indicated that (READ NAMES OF PERSONS RESPONDENT LISTED AS "SOMEWHAT" OR "VERY UPSETTING IN ANY CATEGORY IN PART H) were somewhat or very upsetting to you. How have you tried to deal with (NAME EACH IN ORDER?

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8. (HAND CARD F). Please look at this card. Which of these income groups represents your total combined family or household monthly or yearly income. Include income from all sources, such as wages, salaries, retirement income, rent from property, and so forth.

Monthly	**Yearly**	**Code**
A. Less than $1,250	Less than $15,000	1
B. $1,250 - $2,000	$15,000 - $24,000	2
C. $2,001 - $4,000	$24,000 - $48,000	3
D. Over $4,000	Over $48,000	4
E. DK/RF		9

______
Code

THANK YOU

Biographical Note

Name: William J. Strawbridge

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Secondary Education: Attended the University of Cincinnati, receiving a Bachelor of Arts in 1962 and a Master of Arts in 1964 with a combined major in Sociology/Anthropology. Received a Master of Public Health from the School of Public Health, University of Washington, in 1987.