



U.S. Department of Health and Human Services  
Assistant Secretary for Planning and Evaluation  
Office of Disability, Aging and Long-Term Care Policy

# **FACTORS ASSOCIATED WITH ENDING CAREGIVING AMONG INFORMAL CAREGIVERS TO THE FUNCTIONALLY AND COGNITIVELY IMPAIRED ELDERLY POPULATION**

February 1990

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This report was prepared under grant #88ASPE209A between the U.S. Department of Health and Human Services (HHS), Office of Social Services Policy (now DALTCP) and Johns Hopkins University. For additional information about the study, you may visit the DALTCP home page at [http://aspe.hhs.gov/\\_/office\\_specific/daltcp.cfm](http://aspe.hhs.gov/_/office_specific/daltcp.cfm) or contact the ASPE Project Officer, Pamela Doty, at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, SW, Washington, DC 20201. Her e-mail address is: [Pamela.Doty@hhs.gov](mailto:Pamela.Doty@hhs.gov).

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ELDERLY POPULATION**

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February 1990

Prepared for  
Office of the Assistant Secretary for Planning and Evaluation  
U.S. Department of Health and Human Services  
Grant #88ASPE209A

The opinions and views expressed in this report are those of the authors. They do not necessarily reflect the views of the Department of Health and Human Services, the contractor or any other funding organization.

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# LITERATURE REVIEW

The stress and burden experienced by many caregivers to the elderly has recently been the focus of considerable research. The general concept of caregiver burden is developed from the stress theory perspective (Romeis, 1989) which focuses on the caregivers ability to cope with the presumed stress of caregiving. Kinney and Stephens (in press) have identified three sources of such stress: characteristics of the impaired elderly person, characteristics of familial and other relationships involved in caregiving, and the behaviors required for caregiving (cited in Lawton, et al., 1989). In addition, the characteristics of the caregiver may be a source of stress.

Recognizing the sources and types of stress experienced by caregivers is a prerequisite to alleviating the burden associated with caregiving. Informal caregivers such as family and friends perform a vital service to disabled elderly people in the community. According to recent national surveys, informal caregiving is currently the dominant mode of providing long term care services to the functionally disabled elderly (Doty, 1986). As the number of elderly people increases, the role of family caregivers may become even more important.

Many investigators believe that caregiver stress leads to decisions to institutionalize recipients of care and that interventions to reduce caregiving burden would prolong caregiving. Some studies suggest the decision to end caregiving and to institutionalize generally follows a period of cumulative stress and fatigue for the caregiver (Colerick and George, 1986; Zarit, Todd, Zarit, 1986). These studies by Colerick and George (1986) and Zarit, Todd, and Zarit (1986) have found that it is the characteristics and the well-being of the caregiver, as well as the caregivers' subjective burden, which are related to the decision to institutionalize a care recipient rather than objective indicators of patient illness or disability.

Research in the area of caregiver burden is generally of two types: studies which focus on conceptual models of burden related to caregiving and empirical studies of the impact of caregiver burden. Comparisons among studies that measure burden are difficult since a wide variety of variables pertaining to caregiver burden have been investigated. This review will define what is generally meant by caregiver burden and will describe the measures of burden most frequently used. In addition, evidence of the impact of caregiver burden with respect to specific physical and emotional health outcomes will be discussed.

## **Defining and Measuring Caregiving Burden**

The stress or burden experienced by a caregiver to a frail elderly person can be defined as physical, emotional, and financial (Cantor and Little, 1985, George and Gwyther, 1986; Horowitz, 1985). These categories can be divided further into objective

or subjective measures of burden. Objective measures of caregiving burden include such factors as time spent on caregiving, tasks performed, health problems that develop, effect on employment, and limitations on one's social life. Subjective burdens are the caregiver's attitudes and emotional response to caregiving. Although subjective burden is more difficult to measure, the importance of caregivers' subjective perceptions and interpretations of the burdens they experience should not be minimized.

Some investigators suggest that the emotional burden which may accompany caregiving is the most pervasive problem and has the most severe consequences (Brody, 1985; Cantor, 1982). Emotional burden may be experienced as depression, demoralization or negative feelings; adverse effects in various spheres of personal or family life; and feelings of embarrassment and overload (Horowitz, 1985). Physical burden may be characterized by difficulties in performing specific caregiving tasks and by deterioration in physical health (Poulshock and Deimling, 1984).

The effects of caregiving are usually conceptualized as unidimensional or as multidimensional (Horowitz, 1985). A unidimensional approach uses instruments, such as the widely-applied Burden Interview developed by Zarit and associates (1980) and the more recent Caregiver Strain Index developed by Robinson (1983), to examine a single aspect of the effects of caregiving, such as emotional burden. Poulshock and Deimling (1984) take a multidimensional approach in their study of 614 families living with and caring for an impaired elderly person. Their study examines the relationship of burden to impairment levels of the recipient and the effects of this burden on the relationship between caregivers and those receiving care. Their research indicates that reported burden correlates with the frail elder's impairment in cognitive functioning, in everyday behaviors such as sociability, and in activities of daily living. These factors in turn affect the quality of the relationship between the caregiver and the frail elderly person and lead to more or less interpersonal conflict, as well as restriction of activities for caregivers.

## **Characteristics of the Care Recipient on the Impact of Caregiving**

As noted by Poulshock and Deimling (1984), most research on the burdens related to caregiving have focused on caring for persons who are cognitively impaired. Many studies use Alzheimer's patients and family support groups as study populations (e.g. George and Gwyther, 1986). A recurring question in the literature is whether there are differences in caregiving burden by whether the recipient is cognitively or only physically impaired (Horowitz, 1985). Some studies indicate that caring for those with cognitive impairment appears to be the most stressful for caregivers (Horowitz, 1985; Cantor and Little, 1985). However, other studies have found the presence of cognitive impairment to be less critical than the specific disruptive behaviors which stem from it (Noelker and Poulshock, 1982; Horowitz, 1985; Cantor and Little, 1985; Zarit, Todd, Zarit, 1986).

In a review of the literature, Silliman (1988) addresses the differences in burden between caring for the cognitively impaired and the physically impaired. The literature she reviews suggests that the demands on caregivers to the physically impaired elderly are different from those on caregivers to the cognitively impaired. For example, elderly people with hip fractures require significant physical effort on the part of the caregiver, whereas patients with dementia are often less physically demanding but may require substantial supervision. Finding time away from caregiving may be very difficult for those who care for the cognitively impaired which may lead to increased stress.

Many additional studies have investigated the negative effects of caring for a frail elderly person. For instance, Zarit, Reever, and Bach-Peterson (1980) describe financial difficulties, role strain, and physical health deterioration from providing care to an elderly relative with Alzheimer's Disease. A study by Coppel, Burton, Becker, and Fiore, 1985, found that 81% of a sample of spousal caregivers of Alzheimer's patients reported the presence of a diagnosable clinical depression at some point during the illness of the care recipient.

George and Gwyther (1986) compared indicators of well-being for those with caregiving responsibilities and similar individuals without these responsibilities (Romeis, 1989). Their study, using a sample of 510 family caregivers providing some level of care to memory impaired older adults, investigated four measures of well-being: physical health, mental health, social participation, and financial resources. They found that the resources available to the caregiver and the caregiving situation affected caregiver well-being more than the condition of the patient. Caregivers, compared to those without caregiving responsibilities, displayed decreased well-being in the areas of mental health and social participation. However, no evidence was found that caregivers experience declines in physical health and financial security relative to those who were not caregivers.

## **The Burden of Cargiving by Characteristics of the Caregiver and the Structure of the Caregiving Relationship**

The burden of caregiving is not felt uniformly by all caregivers (Cantor, 1983). Spouses have different worries than children and report a greater degree of physical and financial strain than children and other relatives (Cantor, 1983). George and Gwyther (1986) also describe the heightened vulnerability of spouse caregivers. They report that spouse caregivers had significantly more doctor visits and poorer self-rated health than adult children and other relatives. Additionally, Fengler and Goodrich (1979) found that although morale was generally low in their study of wives caring for elderly disabled husbands, it was possible to separate the wives into low and high morale groups. The most frequently mentioned problems of the low morale wives were isolation, loneliness, economic hardship, and role overload. On the other hand, the overwhelming concern of children and younger relatives involved with frail elderly people is often their ability to obtain necessary help (Cantor, 1983).



Gender differences have been found in the type of care provided and the coping behaviors of caregivers (Barusch and Spaid, 1989). Fitting, Rabins, Lucas, and Eastham (1986) report that important differences in age and sex of caregivers are related to caregiving burden. Women's subjective reactions to caregiving tend to be more negative than those of men. Research has found that women report higher levels of burden and psychological distress associated with caregiving (Zarit, 1982); lower morale (Gilhooly, 1984); have higher depression scores on the MMPI (Fitting and Rabins, 1985) and report more negative symptoms feelings (Siegler and George, 1983).

Several reasons for women's greater sense of burden have been suggested. Since women caregivers are typically younger than men, they may experience greater "role" overload due to the other responsibilities that compete with caregiving (Fitting and Rabins, 1985). Men are harder to care for than women since they may rely more exclusively on the primary caregiver (Zimmerman, 1986). Male caregivers receive more support from informal and formal sources to ease the burden of care and may cope more effectively with life stresses, and thus, cope more effectively with caregiving (Billings and Moos, 1981).

A study by Barusch and Spaid (1989) attempted to further explore gender differences in caregiver burden. They interviewed 131 spouse caregivers to explore why women typically report greater burden associated with caregiving. Their results suggest that age differences in male and female caregivers contribute to the observed differences in burden. Colerick and George's (1986) longitudinal investigation of 209 caregivers to patients with Alzheimer's Disease elaborated on the gender and age differences found regarding the level of caregiving burden predictive of institutionalization. They found that caregivers who institutionalized their patients were again more likely to be female, younger, employed, and children of the patient.

A study by Young and Kahana (1989) also supported the notion that burden and role strain are not uniform among caregivers. Their study of 183 heart patient-caregiver dyads analyzed gender and relationship singly and jointly with respect to the process and outcome of caregiving. Their results showed consistent patterns of strain with women. In particular nonspousal caregivers and daughters were found to experience the most severe caregiving burden.

Deimling, Bass, Townsend, and Noelker (1989) investigated the care-related stress of 180 spouse and adult-child caregivers in both shared and separate residences. Their approach utilized three measures of care-related stress: caregiver reports of physical and/or emotional health decline attributed to caregiving; caregiver perceptions of tension, strain, and upset in family relationships; and caregiver's activity restriction resulting from caregiving. Deimling and his colleagues found that spouse and adult child caregivers in shared households experience similar levels of care-related strain. However, when adult children in shared and separate households were compared considerable differences in strain were found. Adult children who shared households with the care recipient showed significantly greater activity restriction but less relationship strain than adult children in separate households.

Furthermore, strain decreases progressively with decreasing centrality of the relationship. Thus, friends and neighbors appear to be the least involved and register the least amount of strain in the role of primary caregiver (Cantor, 1983). In contrast, spouse caregivers report the greatest degree of strain, especially physical and financial strain. However, emotional strain, unlike physical or financial strain, is unique in that children and other relatives are just as likely to be negatively affected as spouses (Cantor, 1983).

Cantor's (1983) study of a sample of 111 caregivers found that the extent of impact on the everyday life of the caregiver appeared to be clearly related to the closeness of the kinship bond and the availability of the caregiver for continual involvement. As a result, the impact was most severe in the case of spouses, all of whom lived in the same house as the care recipient. The next most severely affected were caregiver children, followed by other relatives. Friends and neighbors were the least affected.

## **The Longitudinal Effects of the Burden of Caregiving**

As the above studies have shown, assisting frail homebound elderly people involves significant strain and often requires changes and adjustments in lifestyle on the part of the primary caregiver. Cantor (1983) has found that the caregivers she studied handled the dilemma of conflicting demands and interpersonal strains not by denial of responsibility but by considerable personal sacrifice. Thus, free time for oneself and opportunities to socialize with friends, take vacations, have leisure time pursuits, and run one's own home were sacrificed in order to provide the time to care for a dependent elderly person. Most caregivers also maintained their relationship with their immediate families and their work situation at considerable personal cost (Cantor, 1983).

Research shows that caregiver's feelings of burden are associated with nursing home placement (Colerick and George, 1986; Zarit, Todd, and Zarit, 1986). The study by Zarit, Todd, and Zarit (1986) of 64 caregivers of dementia patients suggests that caregiver burden is a cumulative process. When demands exceed resources for a significant period of time the decision to institutionalize may result. Their findings are consistent with a model in which the negative impact of caregiving is mediated by the caregiver's perception of stress and coping responses. Not all caregivers find the same problems equally burdensome. They react differently to problem behaviors and they vary in their skills for managing these problems. For example, some caregivers may find incontinence burdensome, while others have more difficulty with repetitive behaviors.

The longitudinal studies by Colerick and George (1986) and Zarit, Todd, and Zarit (1986) suggest that caregiver burden is not directly influenced by the specific behavioral problems of the patient but is mediated by the caregiver's ability to tolerate these problems. Zarit, Todd, and Zarit (1986) found that caregivers' ability to tolerate problem behaviors often increases over time, even though the disease (and behaviors)

may worsen. Caregivers themselves indicate they learn to manage problems more effectively or learn not to let problems bother them as much. The daily routine for providing care which many caregivers establish, although not without its stresses, is not excessively demanding or burdensome.

Winograd, et al. (1987) in their study of 18 Alzheimer's Disease patients and their families also found that both problem-solving coping and emotion-focused coping improve over time. They found that as caregivers learn more about the disease process, gain skills in patient management, and share with others their stress and negative feelings, the caregivers become better able to separate feelings of burden and low morale from intolerance toward the patient's behaviors.

Different caregivers also vary in their ability to tolerate stress. Spouse caregivers, possibly due to their enhanced sense of commitment to the care recipient, display a strong tendency to cope with the burdens of caregiving often until deterioration of their own health prevents them from providing care. Colerick and George (1986) found that one of the factors which significantly reduced the probability of institutionalization was the relationship of the caregiver to the patient, spouses being much less likely than others to institutionalize the patient. However, Zarit, Todd, and Zarit (1986) found that despite initial differences in subjective burden between husbands and wives, there were none two-years later. Although, children, followed by other relatives, friends, and neighbors, appear to have lower tolerance for the burden of caregiving than spouses.

In addition to learning how to tolerate stressful behaviors among care recipients, caregivers must continually renegotiate management strategies for caregiving (Colerick and George, 1986). Although the health status of the frail older adult may change, the frequency of memory or behavior problems may not increase. For example, Zarit, Todd, and Zarit (1986) found that as the patient's dementia worsened, some behaviors diminished in frequency or ceased altogether. Some of the most troublesome behaviors experienced with dementia patients such as wandering, paranoid accusations, and restlessness, were no longer manifested at the two-year follow-up. In contrast, the number of difficulties with activities of daily living were found to increase. Thus, caregiving demands for care recipients with dementia shift over time, but do not necessarily increase as patients move from moderate to severe levels of cognitive impairment.

## **Summary and Direction for Future Research**

Overall, these studies suggest that the responsibilities of caregiving are burdensome for different people in different ways. In some studies personal characteristics of the caregiver appear most important while in others the level or nature of care required was more significant. Some of the variations in these results may be due to small samples of different types of caregivers to recipients with various diagnoses. In addition a heterogeneous mix of variables as well as different indices are

used to measure stress and strain. Finally, differences in regional or socioeconomic characteristics may contribute to inconsistencies among the studies.

Future studies need to approach caregiving burden from the perspective of both the caregiver and the care recipient in the context of their specific caregiver relationship. In addition, the activities which are most burdensome for caregivers need to be determined. The heterogeneity of the caregiving experience must be further explored, as well as the implication of caring for people with different types of impairment. At a minimum, future studies need to differentiate between the strain of caregiving that is serious enough to adversely affect the continuation of the caregiver relationship and those strains which are transitory or existed prior to the need for caregiving (Romeis, 1989).

# MEASURES AND PRELIMINARY FINDINGS

## Definitions of Key Variables

**Primary Caregivers:** Those caregivers who were the sole caregiver or who took main responsibility for the elderly person. Each Sample Person (ie. care recipient) has a primary caregiver (n= 1327 primary caregivers). In 47 cases, two people claimed "main responsibility" and both were retained as primary caregivers. In three cases there were three primary caregivers. Primary caregivers were not defined by relationship and included persons who were a spouse, child, other relative or nonrelative to the recipient.

**Ending Caregiving:** The dependent variable in this study was ending caregiving (87 cases). Ending caregiving occurred when the caregiver stopped providing care because the care recipient entered a nursing home or other institution or the caregiver reported being no longer able to provide care, that the recipient was getting other care or was caring for him/herself. Cases in which caregiving ended because the recipient died were excluded (145 cases). An additional 66 ex-caregivers who were secondary caregivers also are excluded from this study.

## Description of Tables

**Table 1:** Table 1 provides the unweighted number of current primary caregivers and ex-caregivers by selected characteristics.

**Table 2:** This table compares the distribution of caregivers by relationship to recipient in two studies, both using the ICS. Stone et al. (1986) indicate that among all caregivers a little over a third were spouses, close to two-fifths children and about a quarter were "others". The current study focuses on primary caregivers and as might be expected a higher proportion of these individuals are spouses, close to half. Together, spouses and children account for 83% of all primary caregivers.

**Table 3 and Table 4:** Table 3 represents characteristics of current primary caregivers (weighted) and Table 4 represents the same characteristics among ex-caregivers (weighted). (Ex-caregivers are restricted to those who stopped giving care for reasons other than death of recipient.) Comparing, current caregivers to ex-caregivers indicates ex-caregivers are:

- Less likely (32.8% vs. 49.5%) to be a spouse of the care recipient and more likely to be a daughter (35.7% vs. 28.2%).
- More likely to be divorced or separated (14.7% vs. 8.4%).
- More likely to be in the highest income group (300%+ of poverty) (24.8% vs. 16.1%).

- Twice as likely to be in the youngest age group, ages 14 to 44, (24.2% vs. 11.5%) since they are more likely to be daughters or other relatives.
- More likely to be in households with three or more individuals (indicating they have a family of their own) (26.9% vs. 15.7%).

**Table 5:** Table 5 describes characteristics of current primary caregivers by cognitive impairment of the care recipient (weighted). The Short Portable Mental Status Questionnaire (Pfeiffer, 1975) was used to determine cognitive impairment in the 1982 NLTCs. About three-quarters of the sample answered the SPMSQ and anyone with three or more errors was regarded as cognitively impaired. If education was less than eight years an additional error was allowed. For persons who did not answer the SPMSQ, a proxy response concerning the sample person's mental state was used.

- One third (32.8%) of recipients receiving care from informal caregivers are cognitively impaired.
- Caregivers who are 45-64 years old are more likely than other caregivers to care for recipients who are cognitively impaired.
- Female caregivers are more likely than males to take care of recipients who are cognitively impaired (35.8% vs. 24.4%).
- Non-white caregivers care for a greater percentage of cognitively impaired recipients (46.8% vs. 30.3%). This finding should be interpreted with caution due to the small numbers of non-whites in the data set.
- Caregivers who are children and other relatives are more likely to care for cognitively impaired recipients (daughter (42.2%), son (38.4%), other relative (38.5%).
- Caregivers who have a secondary caregiver available are more likely to care for a cognitively impaired recipient than those who do not (38.2% vs. 26.7%).
- Caregivers with 4 or more people in their household are more likely to care for cognitively impaired recipients.

**Table 6:** Table 6 reflects characteristics Of current primary caregivers by specific vulnerabilities (age 75+; below poverty; in fair or poor health; and with one or more ADLS). Among current caregivers 17.2% are 75 or older, 16.0% are poor, 38.6% report their health as fair or poor, and 5.3% report being limited in one or more activities of daily living. In addition:

- Of caregivers whose household income is below the federal poverty level, three-fourths (72.3%) are female and more than one quarter (29.5%) is non-white.
- Of those caregivers who are age 75 or older, 88.9% are married to the person receiving care.
- Of caregivers who report fair or poor health, about two thirds (68.0%) are women and 17.3% are non-white.
- Of those caregivers with one or more ADLS, three-fourths (73.4%) are women--two-thirds are spouses and one-quarter are daughters.

- Within each group of "vulnerable" caregivers, over half indicate they do not have a secondary caregiver available, a higher percentage than generally occurs for caregivers overall.

**Table 7:** This table shows age of caregiver by characteristics of recipients of care.

- 21.4% of all caregivers care for someone age 85 or older.
- 53.4% care for a person with three or more ADLS.
- 84.5% care for a person with three or more IADLS.
- One-third care for a person who is both functionally limited and cognitively impaired.
- Caregivers under age 64 are likely to be caring for an aging parent. Among 45 to 64 year old caregivers, 27.7% care for a person 85 or older and 69.6% care for someone 75 or older. Among younger caregivers (14-44 years old) the recipient of care is more often below age 85 and 56.8% are below age 75.
- A much higher percentage of those being cared for by 45 to 64 year old caregivers are cognitively impaired (41.0%) compared to 22.4% for younger caregivers).
- Levels of ADL and IADL impairment, among those being cared for, are about the same between caregivers under age 45 and those 45 to 64.

**Table 8:** Table 8 shows the poverty level of current primary caregivers by characteristics of recipients of care.

- Caregivers in the highest income groups are more often caring for someone 85 or older (30.9% compared to 15.6% in the lowest income group). These are probably more often children in the work force which accounts for higher incomes.
- Levels and types of impairment of recipients of care do not differ greatly within caregiver income levels.

**Table 9:** Table 9 displays the health status and physical impairment of current primary caregivers by characteristics of recipients of care.

- Caregivers with one or more ADLS are more likely to care for someone below age 75.
- Levels and types of impairment of recipients of care do not differ greatly by whether caregivers report their health as excellent/good or fair/poor.
- Caregivers with one or more ADLS themselves are less likely to care for severely ADL-impaired people. 21.8% care for someone with no ADLS. However, 48.5% care for someone with 3 or more ADLS. In addition, they are as likely as caregivers with no ADL impairment to care for IADL-impaired or cognitively impaired individuals.

**Table 10 and Table 11:** These are preliminary tables which show aspects of caregiving or recipient behavior as relate to instrumental (Table 10) and emotional (Table 11) burden. These two tables show variables by whether differences between the responses of current and excaregivers were or were not statistically significant.

<b>TABLE 1. Unweighted Number of Current Primary Caregivers and Ex-Caregivers by Selected Characteristics</b>		
<b>Characteristics</b>	<b>Primary Caregivers</b>	<b>Excaregivers*</b>
Total	1240	87
<b>Age**</b>		
14-44	141	21
45-64	483	32
65-74	400	23
75+	214	11
<b>Sex</b>		
Male	331	21
Female	909	66
<b>Race</b>		
White	1063	78
Other	177	9
<b>Relationship</b>		
Spouse	609	28
Daughter	352	32
Son	77	4
Other***	171	19
Non Relative	31	4
<b>Poverty Level</b>		
<100%	207	16
100-149	240	13
150-200	175	9
200-299	252	16
300+	193	22
Missing/DK	173	11
<b>Marital Status****</b>		
Married	923	60
Widowed	96	6
Divorced/Separated	103	13
Never Married	113	8



TABLE 1 (continued)		
Characteristics	Primary Caregivers	Excaregivers*
Health Status		
Excellent	253	17
Good	502	37
Fair	360	22
Poor	125	11
ADL		
None	1172	81
1+	68	6
Secondary Caregiver Available*****		
Yes	625	N/A
No	608	N/A
Number in Household*****		
1	40	5
2	1007	59
3	106	13
4+	86	10
<p>* Excludes caregivers who stopped giving care because recipient died.  ** 2 cases with unknown age among current caregivers.  *** Includes sons and daughters-in-law, siblings, and other relatives.  **** 5 cases with unknown marital status among current caregivers.  ***** 7 cases unknown if secondary caregiver available among current caregivers.  ***** 1 case number in household unknown among current caregivers.  N/A Not applicable.</p>		

TABLE 2. Distribution of Caregivers By Relationship in Two Studies Using the ICS		
	Stone, Cafferata, Sangl* 1986	Kasper, Steinbach, Andrews 1989
All Caregivers	2,201,000	-----
Primary Caregivers**	-----	1,499,000***
Spouse	35.5%	48.4%
Child	37.4%	34.6%
Other****	27.1%	16.9%
<p>* Stone, R., G.L. Cafferata, and J. Sangl. (1986.) Caregivers of the Frail Elderly: A National Profile. U.S. Department of Health and Human Services. Public Health Service.  ** People who either are the sole caregiver or have the main responsibility if there is more than one caregiver. Each SP has a primary caregiver. In 47 instances, 2 people claimed "main responsibility" and both were retained as primary caregivers (in three cases there were three primary caregivers).  *** Both current and excaregivers.  **** Both define "Other" to include: sons and daughters-in-law, siblings and other relatives.</p>		

<b>TABLE 3. Characteristics of Current Primary Caregivers (weighted distributions)</b>		
<b>Characteristics</b>	<b>Total # (in thousands)</b>	<b>Percent</b>
Total	1397	100.0%
<b>Age</b>		
14-44	161	11.5
45-64	541	38.8
65-74	453	32.5
75+	240	17.2
<b>Sex</b>		
Male	371	26.5
Female	1027	73.5
<b>Race</b>		
White	1187	84.9
Other	211	15.1
<b>Relationship</b>		
Spouse	692	49.5
Daughter	394	28.2
Son	85	6.1
Other*	191	13.6
Non Relative	36	2.6
<b>Poverty Level</b>		
<100%	224	16.0
100-149	270	19.3
150-200	196	14.0
200-299	285	20.4
300+	225	16.1
Missing/DK	197	14.1
<b>Marital Status</b>		
Married	1046	74.9
Widowed	106	7.6
Divorced/Separated	117	8.4
Never Married	129	9.2
<b>Health Status</b>		
Excellent	285	20.4
Good	572	41.0
Fair	404	28.9
Poor	136	9.7

<b>TABLE 3 (continued)</b>		
<b>Characteristic</b>	<b>Total # (in thousands)</b>	<b>Percent</b>
<b>ADL</b>		
None	1323	94.7
1+	75	5.3
<b>Secondary Caregiver Available</b>		
Yes	709	50.7
No	688	49.3
<b>Number in Household</b>		
1	44	3.1
2	1134	81.2
3	121	8.7
4+	98	7.0
* Includes sons and daughters-in-law, siblings, and other relatives.		

<b>TABLE 4. Characteristics of Primary Ex-Caregivers* (weighted distributions)</b>		
<b>Characteristics</b>	<b>Total # (in thousands)</b>	<b>Percent</b>
Total	102	100.0%
<b>Age</b>		
14-44	25	24.2
45-64	37	36.1
65-74	27	26.8
75+	13	12.9
<b>Sex</b>		
Male	25	24.8
Female	76	75.2
<b>Race</b>		
White	89	87.3
Other	13	12.7
<b>Relationship</b>		
Spouse	33	32.8
Daughter	36	35.7
Son	4	4.0
Other**	22	22.5
Non Relative	5	5.0

<b>TABLE 4 (continued)</b>		
<b>Characteristics</b>	<b>Total # (in thousands)</b>	<b>Percent</b>
<b>Poverty Level</b>		
<100%	19	18.8
100-149	16	15.6
150-200	10	9.8
200-299	19	18.5
300+	25	24.8
Missing/DK	13	12.5
<b>Marital Status</b>		
Married	71	69.7
Widowed	7	6.5
Divorced/Separated	15	14.7
Never Married	9	9.1
<b>Health Status</b>		
Excellent	18	18.1
Good	43	42.6
Fair	26	25.8
Poor	14	13.6
<b>ADL</b>		
None	94	92.1
1+	8	7.9
<b>Number in Household</b>		
1	6	5.9
2	68	67.3
3	15	15.1
4+	12	11.8
* Excludes caregivers who stopped giving care because recipient died.		
** Includes sons and daughters-in-law, siblings, and other relatives.		

<b>TABLE 5. Characteristics of Current Primary Caregivers by Presence of Cognitive Impairment in Recipient of Care (weighted distribution)</b>			
<b>Characteristics</b>	<b>Total (in thousands)</b>	<b>Percent SP* Cognitively Impaired</b>	<b>Percent SP not Cognitively Impaired</b>
Total	1397	32.8	67.2
<b>Age</b>			
14-44	161	22.4	77.6
45-64	541	41.0	59.0
65-74	453	27.8	72.2
75+	240	30.9	69.1
<b>Sex</b>			
Male	371	24.4	75.6
Female	1027	35.8	64.2
<b>Race</b>			
White	1187	30.3	69.7
Other	211	46.8	53.2
<b>Relationship</b>			
Spouse	692	25.5	74.5
Daughter	394	42.2	57.8
Son	85	38.4	61.6
Other Relative**	191	38.5	61.5
Non Relative	36	26.0	74.0
<b>Poverty Level</b>			
<100%	224	35.6	64.4
100-149	270	34.2	65.8
150-200	196	25.3	74.7
200-299	285	30.6	69.4
300+	225	35.4	64.6
Missing/DK	197	35.4	64.6
<b>Marital Status</b>			
Married	1046	31.4	68.6
Widowed	106	41.0	59.0
Divorced/Separated	117	38.8	61.2
Never Married	129	31.6	68.4
<b>Health Status</b>			
Excellent	285	32.4	67.6
Good	572	31.7	68.3
Fair	404	35.5	64.5
Poor	136	30.1	70.0

<b>TABLE 5 (continued)</b>			
<b>Characteristic</b>	<b>Total (in thousands)</b>	<b>Percent SP* Cognitively Impaired</b>	<b>Percent SP not Cognitively Impaired</b>
<b>ADL Impairments</b>			
None	1323	32.7	67.3
1+	75	34.1	65.9
<b>Secondary Caregiver Available</b>			
Yes	709	38.2	61.8
No	688	26.7	73.3
<b>Number in Household</b>			
1	44	37.2	62.8
2	1134	31.6	68.4
3	121	34.0	66.0
4+	98	42.6	57.4
* Sample Person, i.e. recipient of care.			
** Includes sons and daughters-in-law, siblings and other relatives.			

<b>TABLE 6. Characteristics of Current Primary Caregivers by Specific Vulnerabilities (weighted percents)</b>					
<b>Characteristics of Caregivers</b>	<b>Characteristics of Caregivers</b>				
	<b>Total</b>	<b>Age 75+</b>	<b>Below Poverty Level</b>	<b>Fair/Poor Health</b>	<b>1+ ADL</b>
Number	1397	239	223	540	74
Percent	100.0%	17.2%	16.0%	38.6%	5.3%
<b>Sex</b>					
Male	26.5	44.7	27.7	32.0	26.6
Female	73.5	55.3	72.3	68.0	73.4
<b>Race</b>					
White	84.9	93.1	70.5	82.7	82.6
Other	15.1	6.9	29.5	17.3	17.4
<b>Relationship to Care Recipient</b>					
Spouse	49.5	88.9	58.9	58.7	62.2
Daughter	28.2	0.5	21.2	24.6	25.5
Son	6.1	0.0	5.1	5.8	4.5
Other Relative*	13.6	9.0	10.8	9.3	7.8
Non Relative	2.6	1.6	4.0	1.7	0.0
<b>Marital Status</b>					
Married	74.9	89.5	72.3	79.1	77.9
Widowed	7.6	5.8	6.5	6.3	8.6
Divorced/Separated	8.4	0.5	12.0	7.4	7.7
Never Married	9.2	4.3	9.2	7.1	5.8
<b>Secondary Caregiver Available</b>					
Yes	50.7	43.2	47.0	43.1	52.0
No	49.3	56.8	53.0	56.9	48.0
* Includes sons and daughters-in-law, siblings, and other relatives.					

<b>TABLE 7. Age of Current Primary Caregiver by Specific Characteristics of the Care Recipient (weighted distributions)</b>					
<b>Characteristics of Care Recipient</b>	<b>Age of Primary Caregiver</b>				
	<b>Total</b>	<b>14-44</b>	<b>45-64</b>	<b>65-74</b>	<b>75+</b>
Number (in thousands)	1395*	161	541	453	240
Percent	100.0%	11.5%	38.8%	32.5%	17.2%
	<b>Percent Distribution</b>				
<b>Age</b>					
65-74	41.4	56.8	30.4	56.0	28.3
75-84	37.2	36.5	41.9	24.2	51.3
85+	21.4	6.7	27.7	19.8	20.5
<b>Number of ADL's</b>					
None	8.5	11.1	9.2	8.3	5.6
1-2	38.1	35.1	37.3	39.6	38.7
3-4	31.0	37.4	31.4	27.3	33.1
5-6	22.4	16.4	22.1	24.8	22.6
<b>Number of IADL's</b>					
None	1.7	1.6	1.0	1.8	3.3
1-2	13.8	15.8	12.5	14.4	14.4
3-4	18.8	21.2	17.0	19.1	20.8
5-6	20.4	24.2	20.3	19.1	20.2
<b>7-8</b>	34.7	30.6	38.7	23.8	32.1
<b>9</b>	10.6	6.6	10.5	12.8	9.2
<b>Any Cognitive Impairment**</b>					
Yes	32.8	22.4	41.0	27.8	30.9
No	67.2	77.6	59.0	72.2	69.1
* Excludes 2 cases where age of caregiver was missing.					
** Three or more errors on the cognitive functioning scale or a report of senility by a proxy respondent.					



<b>TABLE 8. Poverty Level of Current Primary Caregiver by Specific Characteristics of the Care Recipient (weighted distributions)</b>							
<b>Characteristics of Care Recipient</b>	<b>Caregivers' Income Level</b>						
	<b>Total</b>	<b>Below Poverty</b>	<b>100-149%</b>	<b>150-199%</b>	<b>200-299%</b>	<b>300%+</b>	<b>Missing/DK</b>
Number (in thousands)	1397	224	270	196	286	225	196
Percent	100.0%	16.0%	19.3%	14.0%	20.4%	16.1%	14.0%
	<b>Percent Distribution</b>						
<b>Age</b>							
65-74	41.5	48.3	45.3	45.4	41.1	22.8	46.8
75-84	37.1	36.1	37.5	34.9	36.4	46.4	30.3
85+	21.4	15.6	17.3	19.7	22.5	30.9	22.9
<b>Number of ADL's</b>							
None	8.5	12.7	9.5	7.3	7.7	6.3	7.0
1-2	38.1	36.0	40.7	37.8	37.0	38.1	39.0
3-4	31.0	31.8	32.5	31.0	32.3	26.4	32.0
5-6	22.4	19.5	17.7	23.8	23.0	29.2	22.0
<b>Number of IADL's</b>							
None	1.7	2.5	0.8	2.8	0.6	0.5	4.0
1-2	13.8	13.7	17.6	14.8	10.9	10.3	15.9
3-4	18.9	17.2	16.6	19.7	25.0	14.6	18.9
5-6	20.4	20.4	21.9	15.8	20.0	18.8	25.5
7-8	34.6	36.1	28.7	35.4	36.2	45.3	26.0
9	10.6	10.0	14.4	11.5	7.2	10.5	9.8
<b>Cognitive Impairment*</b>							
Yes	32.7	35.6	34.2	25.3	30.6	35.4	35.0
No	67.3	64.4	65.8	74.7	69.4	64.6	65.0
* Three or more errors on the cognitive functioning scale or a report of senility by a proxy respondent.							

<b>TABLE 9. Health Status and Physical Impairment of Current Primary Caregiver by Specific Characteristics of the Care Recipient (weighted distributions)</b>					
<b>Characteristics of Care Recipient</b>	<b>Caregivers' Health Status</b>				
	<b>Total</b>	<b>Perceived Health Status</b>		<b>Physical Impairment</b>	
		<b>Excellent/ Good</b>	<b>Fair/ Poor</b>	<b>No ADL's</b>	<b>1+ ADL's</b>
Number (in thousands)	1397	857	540	1323	75
Percent	100.0%	61.3%	38.7%	94.6%	5.3%
	<b>Percent Distribution</b>				
<b>Age</b>					
65-74	41.5	39.0	45.5	41.0	51.2
75-84	37.1	39.2	33.7	37.2	35.7
85+	21.4	21.8	20.8	21.9	13.2
<b>Number of ADL's</b>					
None	8.5	7.7	9.7	7.7	21.8
1-2	38.1	40.3	34.6	38.6	29.7
3-4	31.1	30.0	32.8	31.2	29.4
5-6	22.4	21.9	23.0	22.5	19.1
<b>Number of IADL's</b>					
None	1.7	1.9	1.4	1.8	0.0
1-2	13.8	14.8	12.3	13.6	17.6
3-4	18.9	19.7	17.6	18.6	24.0
5-6	20.4	20.8	19.8	20.3	23.3
7-8	34.6	34.0	35.7	35.1	26.8
9	10.6	8.9	13.2	10.7	8.4
<b>Any Cognitive Impairment*</b>					
Yes	32.7	31.9	34.1	32.7	34.1
No	67.3	68.1	65.9	67.4	65.9
* Three or more errors on the cognitive functioning scale or a report of senility by a proxy respondent.					

**TABLE 10. Preliminary Table on Aspects of Caregiving Related to Instrumental Burden**

Significant Variables*	Percent "Yes" Among Primary Caregivers		
	Current Caregivers	Excaregivers**	Total
Does R have difficulty moving or lifting SP	33.4	47.1	34.3
Does R help SP get around inside	29.5	49.4	30.8
Does R help feed SP	7.1	13.8	7.5
Does R help SP get in and out of bed	32.7	50.6	33.9
Does R help dress SP	47.2	60.9	48.1
Does R help toilet SP	21.4	30.1	22.0
Does R help SP with bedpan	6.9	12.6	7.2
Does R clean up after bladder or bowel accidents	36.9	49.4	37.7
Is R's sleeping interrupted because of caring for SP	47.4	65.5	48.6
Not Significant Variables	Current Caregivers	Excaregivers**	Total
Does R live with SP	85.9	85.1	85.8
Percent helping 7 days a week	90.8	94.3	91.0
Must R take care of SP when R does not feel well	43.1	47.1	43.4
Does R give SP injections	5.8	5.8	5.8
Does R give SP medicine or change bandages	52.4	63.2	53.1
Does R help with catheter or colostomy	2.5	4.6	2.6
Does R help SP bathe	59.7	63.2	59.9

\* Difference between current and excaregivers is significant based on Chi-Square statistic at  $p < .05$ .

\*\* For excaregivers responses are in reference to "the time just before you stopped taking care of SP." Excludes caregivers who stopped giving care because recipient died.

SP = Sample Person, i.e. recipient of care.

R = Respondent to caregiver survey.

<b>TABLE 11. Preliminary Table on Aspects of Caregiving Related to Emotional Burden</b>			
<b>Significant Variables*</b>	<b>Percent "Yes" Among Primary Caregivers</b>		
	<b>Current Caregivers</b>	<b>Excaregivers**</b>	<b>Total</b>
Can SP be left along	76.1	55.2	74.7
Less privacy for Caregiver	25.9	36.8	26.6
Limits Social Life/Free Time	51.9	63.2	52.6
SP caused Caregiver's health to get worse	17.6	26.4	18.1
SP needs constant attention	32.7	47.1	33.7
SP can do for self what R does	19.4	29.9	20.1
Taking care of SP is hard emotionally	43.9	56.3	44.7
<b>Not Significant Variables</b>	<b>Current Caregivers</b>	<b>Excaregivers**</b>	<b>Total</b>
SP embarrasses Caregiver or others	21.5	19.5	21.3
SP becomes upset and yells at Caregiver	38.9	36.8	38.7
SP lapses into senility	25.5	31.0	25.9
SP forgets things	61.4	67.8	61.8
Helping with toileting bothers SP	14.2	20.7	14.6
Does anyone else regularly take care of SP	52.3	60.9	52.9
<p>* Difference between current and excaregivers is significant based on Chi-Square statistic at <math>p &lt; .05</math>.</p> <p>** For excaregivers responses are in reference to "the time just before you stopped taking care of SP." Excludes caregivers who stopped giving care because recipient died.</p> <p>SP = Sample Person, i.e. recipient of care.</p> <p>R = Respondent to caregiver survey.</p>			

# **WHY CAREGIVING ENDS: FACTORS RELATED TO ENDING CAREGIVING AMONG HELPERS TO ADL-IMPAIRED ELDERLY PEOPLE IN THE COMMUNITY**

The growing research literature on caregiving continues to document the stressful nature of caring for functionally disabled elderly people and the potentially harmful effects of caregiver burden (Romeis, 1989; Poulshock and Deimling, 1984; Cantor and Little, 1985; Pruchno and Resch, 1989; George and Gwyther, 1986). The primary focus in this line of research is to assess the effects of caregiving on the physical and psychological well-being of the caregiver. However, aside from diminished well-being, caregiving when burdensome may have behavioral implications. The quality of caregiving may suffer for example (Horowitz, 1978; Tobin and Kulys, 1979). This study investigates one behavioral outcome that is of considerable importance, the decision by a caregiver to end caregiving. In many instances, this is the point at which an elderly person is institutionalized, though a broader definition would include transitions for people in the community from one caregiving arrangement to another.

Two areas of research are pertinent to the issue of ending caregiving, studies of the effects of caregiving on those who provide help and studies of the process of institutionalization. Most studies of caregiving tend to focus on the impact of caregiving for the person providing care (Stoller and Pugliesi, 1989; Cantor and Little, 1985; Lawton, Brody, Saperstein, 1989; Barusch and Spaid, 1989; George and Gwyther, 1989). However, two recent studies of caregivers to dementia patients were concerned with factors that led caregivers to seek nursing home placement for recipients. Colerick and George (1986) in a study of 209 caregivers to Alzheimer's patients found that the caregiver's well-being and characteristics, such as age, employment status and relationship to the recipient, were more important predictors of institutionalization than characteristics of the patient, such as symptom severity and illness duration. Zarit, Todd and Zarit (1986) in a two-year followup of a sample of 64 spouse caregivers also found severity of the patient's symptoms was not related to nursing home placement. The caregiver's feelings of burden were associated with the decision to institutionalize and the ability of caregivers to successfully cope with their situation depended on a number of factors other than severity of illness.

Studies of predictors of institutionalization often focus on variables reflecting characteristics of the recipient (Branch and Jette, 1982; Greenberg and Ginn, 1979; Shapiro and Tate, 1988), though some measure of informal support is usually considered. These studies for the most part find informal support to be related to likelihood of institutionalization even though there is considerable variety in the way informal support is operationalized. Variables used include help from relatives (Greenberg and Ginn, 1979), having none or few children (Palmore, 1976; Greenberg and Ginn, 1979), living alone (Branch and Jette, 1982), and having a spouse at home. Studies that focus on predictors of institutionalization often have limited information

about caregivers, as a result caregiver characteristics or perceptions are rarely included.

The present study examines factors related to ending caregiving among primary caregivers to disabled elderly people living in the community. Ending caregiving is defined in two ways. The first is an indication by a primary caregiver that they stopped providing help for a variety of reasons (excluding death of the recipient). The second reflects institutionalization of the recipient of care over a two-year period.

One objective of the study is to examine the relative importance of several factors which previous research suggests may play a role in ending caregiving. The factors of interest are recipient characteristics, caregiver characteristics, aspects of the caregiving role and perceptions of that role. A second objective of the study is to assess both the increased likelihood and the probability of ending caregiving in the presence of factors predictive of this outcome.

## **Methods**

Data. The data for this study are from the 1982 National Long-Term Care Survey (NLTC) and the Informal Caregiver Survey (ICS). The NLTC is a nationally representative sample of functionally disabled (by ADL or IADL criteria) elderly people and the ICS is a random sample of caregivers to the ADL-impaired members of the NLTC.

The NLTC sampling frame was the population 65 years of age or older eligible for Medicare benefits. Screening interviews were conducted with 36,000 Medicare beneficiaries to identify functionally impaired elderly people living in the community. Any person with 1 or more ADL or IADL limitations lasting or expected to last 3 months or longer was considered functionally impaired. Of the 6,393 individuals identified using these criteria, detailed interviews were conducted with 6,088 concerning functional limitations, assistance provided by others and use of health services (see Manton, 1988; Manton and Liu, 1987 for more details of the NLTC study design).

The Informal Caregiver Survey was administered to a subsample of unpaid caregivers over the age of 14 assisting persons in the NLTC who reported ADL limitations. For each respondent to the NLTC interview, names and addresses of all caregivers, the type of help they gave and whether they were paid was obtained and used to determine the eligibility of caregivers for the ICS. A subsample of 2,089 caregivers was selected for interview and 1,925 interviews were completed. Procedures for selecting the subsample of caregivers resulted in a self-weighting sample representative of the national population of informal caregivers to ADL-impaired elderly people (Tourangeau, 1984).

The present analysis focuses on primary caregivers, people who were the sole caregiver or took main responsibility for the elderly person. From the total ICS sample,

1,417 primary caregivers were identified. The study group was further reduced by eliminating caregivers to people who died between the NLTCS interview and administration of the ICS. The final study group is 1,327 primary caregivers providing assistance to 1,274 functionally limited elderly people in the community. (For 47 people, two caregivers claimed "main responsibility" and for two respondents, three caregivers did so.)

Variables. The dependent variable in this analysis is whether a caregiver has ended caregiving. It is defined in two ways.

**Ending caregiving in the short-term:** This variable makes use of information from the ICS concerning "helpers no longer giving care to sample persons." The ICS was conducted between mid-October and mid-January of 1982-83, following the NLTCS interview period from June to October, 1982. As a result, some of the people named as caregivers in the NLTCS were no longer acting as such when the ICS was administered. These individuals were interviewed using a Questionnaire for Helpers No Longer Giving Care. This questionnaire mirrored the one administered to persons still actively providing help with the exception that respondents were asked to answer questions with reference to "the time just before you stopped taking care of (person's name)".

People who ended caregiving in the short-term are those who said they stopped taking care of the sample person because they were no longer able, because the person gets other care or no longer needs help, or because the person was institutionalized. In 46% of the cases caregiving ended because the recipient was institutionalized. The next most common reason was that the elderly recipient was "getting other care" (23%). Fifteen percent of former caregivers reported they were no longer able to care for the recipient.

The question concerning reasons the caregiver stopped taking care of the respondent was open-ended, so respondents could give more than one response. Since caregivers were not read the list of reasons however, it is difficult to know the full range of reasons that might apply. For example, many caregivers who said they stopped providing care because the recipient was institutionalized might also have said they were no longer able to care for the recipient had they been asked. For this reason, everyone who ended caregiving for any reason, other than death of the recipient, is included. Of the 1,327 primary caregivers, 1240 are current caregivers and 87 are former caregivers.

**Ending caregiving in the long-term:** The NLTCS is a longitudinal survey in which individuals selected for interview in 1982 were reinterviewed in 1984. It is possible to determine institutionalization or death of sample persons over this two year period. Caregiving is regarded as ongoing if the recipient was still in the community in 1984, regardless of intermittent nursing home admissions. Caregiving is viewed as having ended for persons who were institutionalized in 1984 or who were

institutionalized prior to death between 1982 and 1984. Under this definition, among the 1,327 primary caregivers, there are 1157 current caregivers and 170 former caregivers.

**Factors related to ending caregiving:** Independent variables are grouped by whether they reflect recipient characteristics, caregiver characteristics, caregiver role responsibilities, or appraisal of the caregiver role.

Recipient characteristics include age, presence of cognitive impairment, availability of a secondary caregiver and living alone versus with others. The Short Portable Mental Status Questionnaire (Pfeiffer, 1975) was used to determine cognitive functioning. Anyone with 3 or more errors was regarded as cognitively impaired (an additional error for fewer than 8 years of education was allowed). For persons who did not complete the SPMSQ, indications of "senility" by proxies were used (see Kasper, 1990 for definitions of cognitive impairment in the NLTCS sample).

Caregiver characteristics include age, perceived health status (excellent, good, fair, poor), employment status (working or not), income (under \$10,000 versus at or above), presence of children under 18 years of age, and whether the caregiver was a spouse.

Aspects of the caregiver role include numbers of ADL activities with which the caregiver assists (bathing, dressing, eating, getting around inside, getting in and out of bed, and toileting); hours of assistance categorized as under 2 hours or 2 hours and above (in response to "because of recipient's disability how many extra hours do you spend helping on an average day?"); and whether the caregiver reported being unable to leave the recipient alone.

The variables included under appraisal of the caregiver role reflect the caregiver's assessment of the burden and impact of the caregiver role (Lawton et al., 1989). Caregivers were asked whether "taking care of him/her has caused my health to get worse," whether caregiving "is hard on me emotionally," whether the caregiver "ever feels he/she is doing things for the recipient that the recipient can do for him/herself," and whether caregiving "limits my social life or free time."

In addition two other indicators of caregiver appraisal were constructed from questionnaire items. One reflects whether the caregiver viewed the relationship with the person receiving care as in any way reciprocal. The other indicates satisfaction with the caregiving relationship relative to stress.

A view of the relationship with the recipient as reciprocal is indicated if the caregiver said the recipient "was helpful" in any one of a series of five items including "household chores" and "keeps me company." It has been suggested that relationships which are characterized by excessive giving or receiving may be detrimental to participants (Depaulo and Fisher, 1980). Caregivers who feel there is reciprocity also may feel less burdened by caregiving responsibilities.



Lawton et al. (1989) suggests that satisfaction with caregiving is a separate dimension in appraisal of the role. A variable reflecting the ratio of satisfaction to stress was constructed from two indicators: "How many points would you give to show how much stress it causes you to do all of the things you do to help?" and "How many points would you give to show how good it makes you feel to help--the better it makes you feel, the bigger the number you would give." For caregivers whose ratio of satisfaction points to stress points was greater than one--about three-quarters of all primary caregivers--satisfaction related to caregiving was viewed as greater than stress (see Appendix Table A).

## Results

Only a small percentage of people who have taken on the responsibility of caring for elderly people with ADL limitations give up this role--6.8% within an 8 month period (short-term) and 12.8% over two years (long-term)(Table 1). Almost half of primary caregivers are married to the person being cared for (48.4%), and spouse caregivers are a smaller percentage of those who end caregiving (32.8% of those who stop in the short-term, and 39.5% of those who stop in the long-term.) Most other caregivers are overrepresented among those ending caregiving, for example 28.7% of all caregivers are daughters but they represent 35.7% (short-term) to 38.8% (long-term) of those who end caregiving.

Table 2 presents coefficients for univariate relationships between ending caregiving and characteristics of recipients, caregivers, caregiver role responsibilities and appraisal of that role. Among the variables measuring characteristics of recipients and caregivers, only presence of cognitive impairment and a nonspouse caregiver are significantly related to ending caregiving over both the short and long-term. In contrast to some studies of predictors of institutionalization, living alone was not significantly related to ending caregiving. In this sample of ADL-impaired elderly people, only 12% live alone, in contrast to 23% of the disabled elderly in the community (ADL or IADL-impaired) and 130% of elderly people in general (data from the NLTCs and Kasper, 1988) . Thus there may be insufficient numbers of people living alone to assess its impact relative to ending caregiving.

Several caregiver tasks including helping with 3 to 6 ADLs, spending two or more hours a day providing assistance, and being unable to leave the recipient of care alone are all significantly related to ending caregiving. In addition, most of the measures of caregiver role appraisal are related. For characteristics significantly related to ending caregiving, odds ratios are provided indicating the increased likelihood that caregiving will end given the presence of the characteristic of interest.

Lawton et al. (1989) examined a large array of items reflecting the feelings and perceptions of caregivers in an effort to identify the major dimensions on which caregivers assess their role. The three that were identified were subjective burden, caregiving impact (measured in objective behavioral terms) and caregiving satisfaction.

Fewer items reflecting caregiver appraisal are available from the ICS. However, Table 3 indicates that feeling caregiving is emotionally hard is highly correlated with feeling caregiving has worsened health (.38) and limited social life/free time (.40). These items are similar to ones that grouped along Lawton's burden dimension of appraisal. Viewing the relationship as reciprocal and feeling the recipient could do more for him/herself, more closely reflect what Lawton characterizes as the impact of caregiving. The reciprocity variable is based on reports of ways in which the recipient of care helps out, and the second is similar to Lawton's item, "the recipient asks for more help than he/she needs." Correlations of these items with the subjective burden items are less than .20. Based on these relationships, appraisal of caregiving is represented in the multivariable analyses by the following: feeling that caregiving is emotionally hard (subjective burden), viewing the relationship as reciprocal and feeling the recipient could do more for him/herself (impact of caregiving), and whether satisfaction with caregiving is greater than stress (caregiving satisfaction).

Variables significantly related to ending caregiving are entered in separate multivariable analyses for ending caregiving in the short and long-term. For ending caregiving in the short-term, the final model shows significant factors to be whether one is caregiver is a spouse (negatively related), assisting with more ADL tasks, being unable to leave the recipient of care alone, and feeling the stress of caregiving outweighs the satisfaction (Model 3 in Table 4). Though a significant univariate relationship exists between cognitive impairment and ending caregiving in the short-term (Table 3), presence of cognitive impairment is no longer significant once caregiver role variables are introduced. One of the role variables, being unable to leave the recipient, is correlated with presence of cognitive impairment. However the correlation is not high (.17).

Table 5 examines factors significantly related to ending caregiving over a longer period of time and uses a definition of ending caregiving that is the equivalent of institutionalization of the recipient. Model 3 indicates factors related to ending caregiving in the long-term are presence of cognitive impairment in the recipient, whether one's caregiver is a spouse (negatively related), assisting with more ADL tasks, and viewing caregiving as emotionally hard. Since age of caregiver and spouse/nonspouse relationship to recipient were correlated, only the relationship variable was used. In both the short and long-term, a nonspouse caregiver and assisting with 3 or more ADLs are related to ending caregiving.

Appraisal of the role is important as well though a different dimension is significant in each analysis--satisfaction greater than stress in the short-term and viewing caregiving as emotionally hard in the long-term. The reciprocity variable is not related. As it turned out, 90% of caregivers reported the recipient helped in some way so this particular measure of reciprocity may not discriminate reciprocal from nonreciprocal relationships very effectively. The other measure of caregiver impact, whether the caregiver felt the recipient could do more for him/herself, dropped out of the multivariable analyses as well.

Age was related to ending caregiving in the long-term in the univariate analysis. Adding age of the recipient to the model increases the explanatory power of the model (Model 3 + Age, Table 5). This is not surprising since increasing age is consistently shown to relate to greater likelihood of institutionalization (Branch and Jette, 1982; Shapiro and Tate, 1985). Age reduces to nonsignificance the relationship of ending caregiving to two other variables, whether the caregiver is a spouse and the number of ADL tasks with which the caregiver assists (the relationship for ADL tasks borders on significance at  $p=.06$ ). As might be expected, the correlation between having a spouse caregiver and increasing age is negative ( $-.30$  for recipients of care age 85 or above, and  $-.08$  for those age 75 to 84). Both cognitive impairment and an appraisal of the caregiver role as emotionally hard remain related to ending caregiving in this model. Though the introduction of age improves the model, in all likelihood it masks differences among the ADL-impaired elderly in health status and social support that are related to institutionalization.

Table 3, Table 4, and Table 5 indicate the increased likelihood that caregiving will end given the presence of certain factors reflecting characteristics of the recipient of care, the caregiver, the role of the caregiver and his/her appraisal of that role. Several of these factors substantially increase the likelihood that caregiving will end. Nonetheless for events as rare as ending caregiving, the probability of occurrence may still be quite small. Consequently it is important to evaluate whether these factors affect in a meaningful way the magnitude of the probability caregiving will end.

Table 6 indicates the probability that caregiving will end in the presence of characteristics shown to be important in the previous analyses.<sup>1</sup> Several individual factors have an effect. Probability that caregiving will end in the long-term is .14 for cognitively impaired individuals and only .08 for those with no impairment. In the short-term, the probability that caregiving will end is .09 when caregivers do not view satisfaction as greater than stress and .04 when they do. Though most of the factors significantly related to ending caregiving increase the probability of its occurrence, in the short-term no individual factor increases the probability above 10%. In the long-term, feeling caregiving is emotionally hard had the greatest effect, increasing the probability of ending caregiving to 16%.

It has been suggested by other researchers that examining the effects of combinations of characteristics may be a more useful approach to targeting those at risk of events such as institutionalization (Shapiro and Tate, 1988). Given the low probability that caregiving will end, even in the presence of specific characteristics that increase one's risk, this approach is applied here. Overall characteristics taken in combination have a substantial effect on the probability that the primary caregiver ends caregiving. If the caregiver is not the spouse, assists with 3 or more ADLs, is unable to leave the recipient alone and appraises caregiving negatively, there is a 30% chance that caregiving will end in the short-term. The chances of the primary caregiver ending

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<sup>1</sup> The effects of individual characteristics are assessed assigning all other variables in the logistic regression equation to their mean values. See Appendix Table B for mean values and Cleary and Angel, 1984 or numerous statistics texts for formulas for computing probabilities from logistic regression models.

caregiving in the long-term are greater than one in three for a combination of characteristics including cognitive impairment and appraising caregiving negatively. Using age in place of the variables concerning relationship to recipient and level of ADL assistance yields only a small increase in the probability that caregiving ends (.38 versus .36). In the absence of these combinations of circumstances, for example a spouse caregiver performing fewer ADL tasks with a positive appraisal of the caregiving role, the probability of ending caregiving is quite small-- .02 in the short-term, .04 in the long-term (not shown in Table 6).

## Discussion

Most elderly disabled people living in the community rely on family and friends for assistance with routine daily tasks that have become difficult to perform independently. The key role of informal caregivers in providing this care makes it important to understand the factors that contribute to their ability to continue to do so or result in a decision to end caregiving.

Variables on characteristics of recipients of informal care and those acting as caregivers, as well as on caregiving activities and appraisal of the caregiving role, were used in this study to examine ending caregiving in two contexts. These are people who were no longer acting as caregivers within a relatively short period of time (within 8 months) following their identification as a caregiver, and people who were no longer acting as caregivers over a longer period of time because the recipient of care had been institutionalized (within 2 years). Only elderly people with ADL limitations and their primary caregivers--those who take main responsibility or are the sole caregiver--are included.

At the outset it is important to note that despite the difficulties usually associated with providing assistance with routine activities of daily living, only a small percentage of primary caregivers end caregiving in either the short or long-term. Studies of caregiving strain or burden and studies of predictors of institutionalization suggest a wide range of variables might influence who does and does not relinquish the caregiver role. Characteristics of recipients and levels of disability are usually the focus of studies considering factors in institutionalization, while perceptions of stress and burden are seen as more important in understanding caregiver well-being. Both types of variables are included here. In the univariate results few of the recipient characteristics or caregiver characteristics were significantly related. Several aspects of the caregiver's role and indicators of appraisal of that role were important in ending caregiving.

The multivariable results for ending caregiving in the short and long-term are somewhat different, though an aspect of role appraisal, aspects of the caregiver's role and whether the caregiver is a spouse are important in both (Model 3, Table 4 and Table 5). Different appraisal variables were related in the short-term and long-term. Viewing caregiving as providing greater satisfaction than stress was negatively related to ending caregiving in the short-term and finding caregiving emotionally hard was

positively related in the long-term. The interpretation of this difference is not clear. One possibility is that because ending caregiving in the short-term included changes in caregiving that were less drastic than institutionalization, different aspects of appraisal come into play. Another is that there may be a sequence to the appraisal process. People who ended caregiving over the short-term were much closer to the point of stopping than most of those who ended caregiving over the long-term. There is little empirical evidence concerning how the dimensions of caregiver appraisal change over time or are expressed in behavioral terms, such as the decision to end caregiving.

Cognitive impairment and age are the two recipient characteristics important in ending caregiving over the long-term i.e. institutionalization of the recipient. Cognitive impairment is not related to ending caregiving in the short-term once other variables are taken into account, though it is correlated with inability to leave the recipient which was related. Including age of the recipient in the multivariable model for ending caregiving over the long-term improved the fit. However, age is probably a proxy for additional differences in health status and social support that contribute to ending caregiving.

Ending caregiving is a rare event. Though the variables identified increase the likelihood that caregiving to an ADL-impaired elderly person will end, no single variable is a particularly good predictor of the probability of ending caregiving. Even the presence of significantly related factors such as cognitive impairment, do not increase the probability that the primary caregiver will end caregiving beyond 10 to 15 percent. However, the probability that caregiving will end is greatly increased when several factors related to ending caregiving occur in combination. By examining combinations of variables related to ending caregiving, it may be possible to develop profiles of caregivers who are at risk of ending caregiving and in need of intervention such as external support or assistance. In addition, it seems clear that what the caregiver does and his/her appraisal of the role are important components of this profile. Of the individual characteristics, the variables reflecting appraisal of the caregiver role discriminated most strongly between the probability of ending or continuing caregiving (Table 6).

Finally, further research on the dynamics of changes in caregiving is needed to understand how various characteristics contribute to ending caregiving over time. If support to informal caregivers is an important policy consideration, it is necessary to know not only which combination of characteristics warrants assistance and intervention but when in the process to intervene. When the probability of ending caregiving becomes too great, no amount of intervention or assistance may be able to alter the outcome.

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<b>TABLE 1. Distribution of Primary Caregivers to ADL-Impaired Elderly People by Relationship to Care Recipient</b>				
	<b>Primary Caregivers* (N)</b>	<b>Primary Caregivers</b>		
		<b>All</b>	<b>Ending Caregiving Over</b>	
			<b>Short- Term**</b>	<b>Long- Term***</b>
Total	1327	100.0%	6.8%	12.8%
<b>Relationship to care recipient</b>				
Total		100.0%	100.0%	100.0%
Spouse		48.4	32.8	39.5
Daughter		28.7	35.7	38.8
Son		5.9	4.0	4.4
Other relative****		14.2	22.5	13.1
Non relative		2.7	5.0	4.1
<p>* Sole caregiver or person claiming main responsibility for caregiving.  ** Within 8 months of care recipient interview. Definition excludes death of recipient as reason caregiving ended and includes institutionalization, unable to continue as caregiver, recipient gets other care or no longer needs help.  *** Within 24 months of care recipient interview. Includes all instances in which recipient was institutionalized prior to death or at the 2-year follow-up interview.  **** Includes sons-in-law and daughters-in-law, siblings and other relatives.</p>				



**TABLE 2. Factors Related to Ending Caregiving Among Primary Caregivers  
(univariate logistic regression)**

	Primary Caregivers Ending Caregiving Over			
	Beta	Odds Ratio	Beta	Odds Ratio
Recipient Characteristics				
Age				
65-74	-.30	-	-1.18**	.30
75-84	.14	-	.44**	1.56
85+	.21	-	.69**	2.00
Cognitive Impairment	.63**	1.88	.93**	2.53
More than one caregiver	.35	-	.33*	1.39
Lives alone	.48	-	.06	-
Caregiver Characteristics				
Age				
14-44	.91**	2.48	-.18	-
45-64	-.10	-	-.16	-
65-74	-.28	-	-.44*	.64
75+	-.37	-	.44*	1.55
Health Status (Poor=4, Ex=1)	-.05	-	.13	-
Income (Low=1, High=0)	-.32	-	-.24	-
Works	-.12	-	-.06	-
Has children <18 years old	.08	-	-.29	-
Spouse of recipient	-.71**	.49	-.49**	.62
Caregiver Role				
Number of ADL tasks				
None (IADL only)	-.98**	.38	-.67**	.51
1-2	-.21	-	-.20	-
3-6	.84**	2.32	.67**	1.95
Hours of Assistance	.61*	1.84	.61**	1.84
Unable to leave recipient alone	.95**	2.58	.65**	1.91
Appraisal of Caregiver Role				
Satisfaction greater than stress	-.93**	.39	-.47**	.63
Health has worsened	.52*	1.68	.60**	1.83
Emotionally hard	.50*	1.65	1.21**	3.36
Views relationship as reciprocal	.08	-	-.59*	.55
Feels recipient could do more for self	.57*	1.78	.53**	1.69
Limits social life/free time	.47*	1.60	.60**	1.83

\*\* p<.01

\* p<.05

<b>TABLE 3. Spearman Correlation Coefficients Among Variables Reflecting Appraisal of Caregiver Role by Primary Caregivers (Informal Caregivers Survey)</b>					
<b>Appraisal of Role</b>	<b>S</b>	<b>H</b>	<b>E</b>	<b>R</b>	<b>DM</b>
Satisfaction greater than stress (S)					
Health has worsened (H)	-.20	-	-	-	-
Emotionally hard (E)	-.22	.38	-	-	-
Views relationship as reciprocal (R)	.15	-.07	-.11	-	-
Feels recipient could do more for self (DM)	-.13	.14	.19	-.07	-
Limits social life/free time	-.15	.26	.40	-.10	.16
Only correlations with p<.01 shown.					

<b>TABLE 4. Factors Related to Ending Caregiving in the Short-Term (multiple logistic regression)</b>			
<b>Factors Significantly Related in Univariate Analysis</b>	<b>Model 1 (A &amp; B)</b>	<b>Model 2 (A - C)</b>	<b>Model 3 (A - D)</b>
<b>Recipient characteristics (A)</b>			
Cognitive impairment	.53*	.29	.27
<b>Caregiver characteristics (B)</b>			
Spouse of recipient	-.63**	-.62*	-.64**
<b>Caregiver role (C)</b>			
Number of ADL tasks <sup>a</sup>	-	.55*	.51*
Hours of assistance	-	.19	-
Unable to leave recipient alone	-	.64**	.65**
<b>Appraisal of role (D)</b>			
Satisfaction > stress	-	-	-.76**
Emotionally hard	-	-	.02
Feels recipient could do more for self	-	-	.45
Intercept	-2.60	-3.13	-2.57
Model Chi-square <sup>b</sup>	14.95**	34.02**	48.93**
(df)	(2)	(5)	(7)
** Significant at p<.01 * Significant at p<.05 - variable not included a. Helps with 3 to 6 ADLs versus else. b. Indicates a change in deviance from the intercept only model.			

<b>TABLE 5. Factors Related to Ending Caregiving in the Long-Term (multiple logistic regression)</b>				
<b>Factors Significantly Related in Univariate Analysis</b>	<b>Model 1 (A &amp; B)</b>	<b>Model 2 (A - C)</b>	<b>Model 3 (A - D)</b>	<b>Model 3 + Age</b>
<b>Recipient characteristics (A)</b>				
Cognitive impairment	.86**	.73**	.67**	.55**
More than one caregiver	-	-	-	-
Age 75+	-	-	-	.93**
<b>Caregiver characteristics (B)</b>				
Spouse of recipient	-.32*	-.34*	-.41*	-.14
<b>Caregiver role (C)</b>				
Number of ADL tasks <sup>a</sup>	-	.38*	.36*	.33
Hours of assistance	-	.32	-	-
Unable to leave recipient alone	-	.30	-	-
<b>Appraisal of role (D)</b>				
Satisfaction > stress	-	-	-.13	-.10
Emotionally hard	-	-	1.01**	1.00**
Views relationship as reciprocal	-	-	-.21	-.14
Feels recipient could do more for self	-	-	.27	.26
Intercept	-2.18	-2.56	-2.51	-3.30
Model Chi-square <sup>b</sup>	35.08**	47.74**	86.46**	105.90**
(df)	(3)	(5)	(7)	(8)
** Significant at p<.01 * Significant at p<.05 - variable not included a. Helps with 3 to 6 ADLs versus else. b. Indicates a change in deviance from the intercept only model.				

<b>TABLE 6. Probabilities of Ending Caregiving by Primary Caregivers to ADL-Impaired Elderly People in the Community for Characteristics Singly and in Combination</b>		
<b>Characteristics</b>	<b>Probability That Caregiving Ends in</b>	
	<b>Short-Term</b>	<b>Long-Term</b>
Individual characteristics significantly related in Model 3 <sup>a</sup>		
Age:		
<75	-	.06 <sup>b</sup>
75+	-	.14 <sup>b</sup>
Cognitive impairment:		
yes	-	.14 <sup>b</sup>
no	-	.08 <sup>b</sup>
Spouse caregiver:		
yes	.04	.09
no	.07	.12
Number of ADL tasks:		
<3	.04	.09
3-6	.07	.13
Satisfaction > stress:		
yes	.04	-
no	.09	-
Emotionally hard:		
yes	-	.16 <sup>b</sup>
no	-	.07 <sup>b</sup>
Unable to leave recipient alone:		
yes	.04	-
no	.08	-
Effects of characteristics in combination		
No spouse caregiver, 3-6 ADL tasks, unable to leave recipient alone, negative role appraisal <sup>c</sup> (Model 3, Table 4)	.30	-
Cognitive impairment, no spouse caregiver, 3-6 ADLs, negative role appraisal <sup>c</sup> (Model 3, Table 5)	-	.36
Cognitive impairment, age 75+, negative role appraisal <sup>c</sup> (Model 3 + age, Table 5)	-	.38
<p>a. All other variables in the model set to mean values.</p> <p>b. Uses logistic regression equation from Model 3 + Ages in Table 5.</p> <p>c. Negative role appraisal: satisfaction &gt; stress = no, emotionally hard = yes, views relationship as reciprocal = no, feels recipient could do more for self = yes.</p>		

## APPENDIX TABLES

<b>TABLE A. Distribution of Cases on Ratio of Satisfaction to Stress</b>			
<b>Appraisal of Caregiving Role*</b>	<b>All Primary Caregivers (N)</b>	<b>Spouse Caregiver</b>	<b>Child/Other Relative Caregiver</b>
Total	1327	647	690
More satisfying than stressful	999	74.4%	75.9%
Feelings of satisfaction and stress are equal	184	13.0%	14.6%
More stressful than satisfying	144	12.4%	9.4%

\* Based on ratio of responses to two questions. The first is "How many points would you give to show how much stress it causes you to do all of the things you do to help sample person?" The second question is "How many points would you give to show how good it makes you feel to help sample person?--the better it makes you feel, the bigger the number you would give."

<b>TABLE B. Means and Standard Deviations for Independent Variables Used in Regression Equations (Table 6)</b>		
<b>Variables</b>	<b>Mean</b>	<b>Standard Deviation</b>
<b>Recipient Characteristics</b>		
Age		
75+	.60	.49
Cognitively Impaired	.31	.46
<b>Caregiver Characteristics</b>		
Spouse	.48	.50
<b>Caregiver Role Characteristics</b>		
Number of ADL tasks		
3-6	.38	.49
<b>Appraisal of Caregiver Role Characteristics</b>		
Satisfaction greater than stress	.75	.43
Health has worsened	.18	.38
Caregiving is emotionally hard	.45	.50
Views relationship as reciprocal	.90	.30
Feels recipient could do more for self	.20	.40