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Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy

CAREGIVER BURDEN AND INSTITUTIONALIZATION, HOSPITAL USE, AND STABILITY OF CARE:

FINAL REPORT

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This report was prepared under contract #HHS-100-01-0025 between HHS's Office of Social Services Policy (now DALTCP) and the University of Illinois. For additional information about this subject, you can visit the DALTCP home page at http://aspe.hhs.gov/_/office_specific/daltcp.cfm or contact the office at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C. 20201. The e-mail address is: webmaster.DALTCP@hhs.gov. The Project Officer was Pamela Doty.

CAREGIVER BURDEN AND INSTITUTIONALIZATION, HOSPITAL USE, AND STABILITY OF CARE:

Final Report

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TABLE OF CONTENTS

LIST OF TABLES

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EXECUTIVE SUMMARY

This study assessed a variety of longitudinal models to examine the effect of different types of caregiver burden on outcomes important to policy makers: nursing home admissions, hospital use, and stability of the family and formal care network. Burden is defined as the caregiver's appraisal of the balance between level of care demands, level of resources available, and quality of caregiver-care recipient relationship. We distinguished two dimensions of burden: personal burden affecting the caregiver's choice of personal actions and activities, and interpersonal burden affecting the interpersonal relationship between the caregiver and the care-receiver. Nursing home admissions represent the largest and most costly component of long-term care, and hospitalization is the most costly component of health care. Stability of the family care network represents the family response to potential "burnout" by overburdened caregivers. Changes in informal and formal networks of assistance may alleviate burden by shifting or rearranging demands among network participants.

The objectives of the study were: (1) to describe two-year changes in health status, functional abilities, sources of informal care and living arrangements of a subsample of frail elders cared for by their spouses or adult children in 1982; (2) to assess the effect of caregiver burden on nursing home admission, hospital use, and caregiver stability in 1984, controlling for level of elder impairment, socio-economic status, gender, and age. Our assessment contained a number of unique attributes in its use of a national probability survey of caregivers linked to a longitudinal survey of frail elders, containing data from both the caregiver's and frail older person's perspectives and inclusion of a range of long-term care outcomes for an heterogenous group of people who are at high risk for these outcomes. The study also included detailed measurement of a multi-dimensional concept of caregiver burden, to focus on the longitudinal effect of caregiver burden within the context of changing functional limitations.

The data were drawn from the 1982-1984 National Long-Term Care Survey (NLTCS) and the Informal Caregivers Survey (ICS). The NLTCS of frail older persons investigated the demographic characteristics, health and functioning, and patterns of assistance of a national sample of non-institutionalized persons 65 years of age or over. The ICS was conducted in 1983 with a sub-population of informal helpers, 14 years or older, who were identified by a random sample of the NLTCS respondents. The sample analyzed in this study was further restricted to a subset of older persons who had sole spouse and adult child caregivers in 1982, resulting in a 1982 base sample of 940 caregivers that included 351 wives (37 percent), 203 husbands (21.6 percent), 304 daughters (32.3 percent) and 82 sons (8.7 percent) and the frail older persons they assisted. In 1984, 644 older persons from this subsample were still living in the community and form the basis for most of the longitudinal analyses.

We organize our summary of results by general longitudinal effects and results pertaining to burden and other correlates of our major outcome variables. Distinct multivariate models were developed for each outcome.

General Longitudinal Effects

- Two-thirds of the baseline sample were community residents two years later; one-fourth had died, and 7 percent were nursing home residents. Males, non-whites, and those with greater ADL limitations had higher mortality rates.

- Approximately 40 percent were hospitalized in each time period. Of those hospitalized, about 50 percent reported hospitalizations at both time periods.

- Informal task support networks show greater stability in composition and size than change, with a slightly higher degree of change in the level of help provided. Specifically, household size was most stable, followed by slightly more fluctuation in the number of informal helpers, and even more fluctuation in the amount of informal persons days of help.

- Although smaller in scope and use, formal networks had greater instability over the two years, responding more to time-specific needs than the informal care network. There was a general trend to increase use in formal help over time, but over three-fourths of the sample did not use any formal helpers at any time during the study period.

Nursing Home Admissions

- Nursing home admissions were associated with being older, white, more severe ADL and IADL limitations, use of formal helpers, and both types of caregiver burden at the bivariate level.

- Nursing home admissions were predicted by interpersonal burden, use of formal helpers, white race, older age, and higher ADL limitations.

Changes in Care Network

- Socio-demographic characteristics of the caregiver and frail older person were rarely associated with change in network size per se. Personal burden of the caregiver was associated with an increase in days of informal and formal help.

- Increased functional disability during the two year period, and poorer health status of the frail older person in 1984, represented by ADL and IADL disability and cognitive problems were associated with larger networks and higher levels of care in both informal and formal helper networks.

- Those with high levels of personal burden were more likely to report changes in formal helpers in response to changes in informal helpers than those with low levels of personal burden.

- Changes in informal task support networks were predicted by changes in ADL and IADL limitations, but not personal or interpersonal burden.

- Changes in the use of formal services were predicted by personal burden, greater ADL and IADL limitations, prior hospitalization, prior use of formal helpers, fewer informal helpers, older age of the frail person, and higher per-capita income.

Hospitalization

- Hospitalization reports in 1984 were associated with previous hospitalization, number of chronic conditions, and having a spouse caregiver. The number of admissions was associated with lack of a regular source of care and chronic conditions.

- The only significant predictors of hospitalization in 1983-1984 were previous hospitalizations in 1982, the number of chronic conditions of the older person, and caregiver relationship. Neither personal nor interpersonal burden had any effect on hospital use by the frail elderly.

Each dimension of burden influenced a different outcome. The primary effect of personal burden, when controlling for other relevant variables, was on the use of formal services. The link between personal burden and use of formal helpers, especially in the context of increased dependency of the frail older person, suggests that the confinement associated with intense care is handled by bringing in other helpers, if services are available. The primary effect of interpersonal burden, when controlling for other variables, was on the risk of nursing home admission. This result suggests that when the cognitive and affective bonds that link family members together are either seriously disturbed or no longer present, a limit to the degree of reciprocity and obligation engendered by past relationship histories may be reached. Breaking the traditional bounds of the obligation for family care through institutionalization may appear the only way to respond to balance generational and individual family needs within the individual family system.

The results of this study support the importance of developing more specific models linking service programs to populations targeted by level and type of burden, as well as level of impairment of the frail person, and characteristics of the helper network. An important next step is to determine which service combinations/options would meet the different types of burden experienced by the caregiver.

I. CAREGIVER BURDEN AND INSTITUTIONALIZATION, HOSPITAL USE AND STABILITY OF CARE

Family members provide more than 80% of the long-term care for the 20-25% of U.S. elders who are functionally disabled (Day, 1985; Stone et al., 1987), with occasional supplementary use of formal resources. The National Channelling Demonstration Study found that many of the elderly became eligible for services because family members were unable, for a variety of reasons, to continue previous levels of care or increase to a needed new level of care (Stephens and Christianson, 1986). Thus, an important subgroup of the long-term care population is defined not only by the level and type of assistance needed by the frail family member, but also by the availability and capacity of the informal care network. Even if individuals have identical self-care limitations, different policy and service needs can result from the differential capacity of family members to provide care.

The capacity to provide care has many meanings. Geographical availability of caregivers, economic feasibility, flexibility in life-style patterns, availability of other social supports or services, and individual responses to the stresses and accommodations of family care can affect the capacity of families to provide care for a frail family member. This study focuses on the capacity of the primary caregiver to manage the stresses and accommodations of providing care, a concept often denoted as caregiver burden (Zarit, 1980; Poulshock and Deimling, 1984).

Burden is defined as the caregiver's appraisal of the balance between level of care demands, level of resources available, and quality of caregiver-care recipient relationship (Poulshock and Deimling, 1984). Researchers agree that the concept of caregiver burden is multi-dimensional (social, emotional, relationship with care receiver or others, financial, time demands), but there is little consensus on the most important dimensions or how they are connected. in practice, most measures of burden are unidimensional (for example, see the Burden Inventory (Zarit et al, 1980); Robinson's (1983) 13-itern Caregiver Strain Index; and Kosberg's Cost of Care Index (1986)) and there is only limited overlap in the items in each scale. The underlying assumption of these measures is that the additive effects of the problems associated with providing care to an impaired elder are more important than the type of problem experienced. Although the "pile-up" of events may be an important component of family stress (McCubbin et al., 1983), reliance on summary scores conceals dimension specific patterns of caregiving appraisal and impact (George & Gwyther, 1986). In this study, we distinguish two dimensions of burden: personal burden affecting the caregiver's choice of personal actions and activities, and interpersonal burden affecting the interpersonal relationship between the caregiver and the care-receiver.

This report examines the long-term effects (two years) of these two dimensions of caregiver burden using data from the 1982-1984 Department of Health and Human Services National Long Term Care Surveys (NLTCS). Specifically, we assess a variety of longitudinal models to examine the effect of different types of caregiver burden on three outcomes important to policy makers: nursing home admissions, hospital use, and stability of the family care network. Nursing homes represent the largest component of long-term care. Despite much discussion that caregiver burden is a major contributor to nursing home placement decisions, there are few empirical tests of this proposition. Hospitalization is the most costly component of health care. Only a few anecdotal claims have been made for the role of caregiver burden in hospitalization, particularly since the introduction of prospective payments in Medicare. The supposition is that patients without family support may remain in the hospital longer or experience higher readmission rates. We will examine if caregiver burden contributes to more frequent or more lengthy hospitalizations. Stability of the family care network represents the family response to potential "burnout" by overburdened caregivers. Changes in informal and formal networks of assistance may alleviate burden by shifting or rearranging demands among network participants, or create additional sources of burden if needed helpers drop out of a network.

This study grew out of earlier work which examined the simultaneous effect of health, task involvement and subjective stress on two dimensions of burden (Miller, McFall and Montgomery, 1988). We found that functional limitations was a primary contributor to burden, although its contribution was shaped by level of task involvement and global stress. The cross sectional analysis suggested that family caregivers increased their task involvement in response to greater disability in their frail family member, and this increased involvement was associated with higher stress and increased personal and relationship burden. The effects of other dimensions of health, cognitive status and global health on burden outcomes were smaller. This prior work showed that each type of burden had different patterns of association with the health variables. Interpersonal burden was influenced by cognitive dysfunction and use of a proxy respondent, whereas personal burden was directly influenced by perceived health status.

The objectives of the study were: 1) to describe two-year changes in health status, functional abilities, sources of informal care and living arrangements of a subsample of frail elders cared for by their spouses or adult children in 1982; 2) to assess the effect of caregiver burden on nursing home admission, hospital use, and caregiver stability in 1984, controlling for level of elder impairment, socioeconomic status, gender, and age. We examined three research questions:

1. What is the effect of family caregiver's burden on risk of nursing home admission? Specifically, controlling for the frail person's level of impairment, does the caregiver's level of burden in 1982 predict nursing home admission between 1982 and 1984?

2. What is the effect of family caregiver's burden on hospital use by the frail elderly? Specifically, controlling for the frail person's level of impairment, does the caregiver's level of burden in 1982 predict hospital use in 1983-1984?

3. How stable are sources of family caregiving over a two-year period? Are changes in the dimensions of the family care and formal care network associated with prior caregiver burden, controlling for the frail person's level of impairment?

Significance of the Study

Knowledge of the factors that sustain family willingness and ability to provide care is of policy importance from two perspectives. The first perspective emphasizes cost containment issues; the second, the interplay between governmental policy, family decision-making and intergenerational equity. The willingness of families to provide care for frail relatives represents a substantial cost savings for public dollars. Functionally disabled persons without stable informal care networks are most at risk for nursing home placement and use of costly community services (Doty, 1986). Even though a review of recent studies concludes that home health care services do not provide necessarily lower cost alternatives to nursing homes, (Weissert, 1985), the more relevant consideration may be the costs of the services provided by the families themselves. Excluding the costs of physical and emotional strains, the opportunity and replacement costs of family caregiving services have been estimated between $7.2 billion and $16.2 billion a year (Paringer, 1983). Those concerned about cost containment advocate support of family caregivers in order to prevent increased use of more costly health-related services that are more likely to be subsidized by governmental and third-party pay sources. The general assumption is that the greater the burdens placed on the caregiver by the requirements of caregiving, the less able the caregiver will be to continue caring in the community and the greater the likelihood of costly nursing home placements (Stephens and Christianson, 1986).

A second perspective recognizes the cost issues, but also recognizes that the emphasis on cost containment shifts the caregiver burden to the family, and in turn to the women in the family (England, 1989). Thus, this perspective focuses more explicitly on issues of family policy, intergenerational equity, and unequal financial status of women. The current lack of national consensus on appropriate divisions of responsibility for frail older persons between the individual, family, and society, has profound implications for understanding the impact of family care on the family. Recognizing the deep preference for home and family care, the policy goal is to provide support for family care in such a way as to prevent excessive burden (Doty, 1986). Thus, the policy debate broadens beyond that of home care alternatives to institutionalization to that of family care for dependents of all ages. The locus of policy interventions broadens from an emphasis on the home to the workplace, e.g. family leave policies, in effort to increase the supply of family caregivers. Both perspectives rarely acknowledge the feminized nature of family care explicitly in discussions of policy options, except to cite the continuance of family care as a social problem because of the greater participation of women in the workplace (Osterbusch et al., 1987; Ungerson, 1987). Current policy initiatives associated with family caregiver burden vary in whether the caregiver or care receiver is seen as beneficiary, and vary further by the governmental unit designated to have control of spending and programmatic content. In general, national policy, focusing primarily on the health needs of frail older persons seeks to define eligibility requirements in an effort to contain spiraling Medicare and Medicaid costs. State community care programs vary considerably, but tend to define eligibility for in-home services in terms of the functional status of the frail older person. Yet, in some states, the willingness of family caregivers to provide care restricts availability of in-home services, since having needs met by a family member automatically precludes eligibility for service (Osterbusch, et al., 1987).

Services directed at the caregiver are most likely to occur at the local level as part of the voluntary service network, or under the sponsorship of national organizations advocating care for specific diseases, e.g., Alzheimer's Association. These services usually take the form of support groups and respite care. Services directed at explicitly meeting the maintenance needs of the frail older person, i.e., home health care or chore service, are more likely to be provided when family support is not available. A recent review of research about the outcome of group interventions to support family caregivers concluded that although caregivers consistently report satisfaction with the interventions, evidence of specific outcomes, such as relief of psychological disturbances, or increased coping abilities, increased use of community services is lacking (Toseland and Rossiter, 1989). These studies also call typical assumptions about family care into question. For example, the results of a large-scale intervention project (Montgomery and Borgatta, 1989) found that family caregivers were difficult to reach and serve, and sought help only in times of crises. Furthermore, the services provided had different effects for spouse and adult child caregivers. The use of community care services appeared to delay nursing home placement among families with adult child caregivers, but encouraged placement by spouse caregivers.

Another facet of the debate is the extent to which provision of community services will "substitute" for the care now provided by allegedly "unwilling" family caregivers. Most studies have concluded that little substitution actually occurs (McKinlay and Tennestedt, 1986; Exploding the Myths, 1987), in part because most family members and their dependent relative prefer informal family care whenever possible. The results of the National Long Term Care Channelling Demonstration found that case-management did not substantially affect care provision by fancily members nor reduce nursing home use (Stephens and Christianson, 1986). Channelling did increase caregiver satisfaction with services used and general life satisfaction, but had no effect on caregiver's reported strains. The interface between formal and informal services is complex and problems of caregivers are not easily relieved by services as currently implemented. (See Kane, 1989, for critique of level of care management services provided in the Channelling study).

These different levels of policy direction and disagreement about spending and service provision levels reflect the lack of national consensus about the best ways to provide care for dependent individuals, regardless of age. Although national recognition of the value of community services for the frail elderly and their families was shown in the recent passage of the Medicare Catastrophic Coverage Act of 1988, it is just as clear from the reactions to the funding provision of this bill, and its omission of support for long-term care costs, that consensus or even a working agreement is far away.

In this report, we address one facet of this debate: the impact over time of caregiver burden in the long term care of the frail elderly. This project contributes to the advancement of scientific knowledge by drawing on a nationally representative sample of frail elders and their caregivers to assess a longitudinal model of the impact of caregiver burden on stability of family care of the frail elderly. Many studies of caregiver burden exist, but most have used non-probability, cross-sectional samples of convenience and produced descriptive rather than explanatory analyses (see Horowitz, 1985 and Cantor and Little, 1985 for reviews). This study is one of the first to examine the longitudinal relationship of family care, hospital use and nursing home services in a heterogeneous national sample of caregivers and care-receivers with data that include both the caregiver's and frail older person's perspectives. In addition, this group contains a high proportion of persons who have been disabled for a considerable period of time. Thus we can examine established patterns of adjustment to chronic care, not responses to crises, and include a range of long-term care outcomes for an heterogenous group of people who are at high risk for these outcomes. Furthermore, we can examine longitudinal effects of caregiver burden in the context of changing functional limitations. We also contribute to the theoretical development of the concept of caregiver burden, by including detailed measurement of two dimensions, distinguishing personal and interpersonal components of burden.

The policy issues of division of responsibility between federal, state, community and individual resources for the care of frail elderly will continue to be unresolved for some time. Resolution of these issues is ultimately dependent on societal and family values, even more than on empirical research results.

Organization of Report

This report is focused on the three analytic questions discussed above. Chapter 2 reviews the methodology of the study, describing the sample and measures, and presents the distribution of change in the major outcome variables. Each analytic chapter uses different subsets of the sample, providing further description as needed. Chapter 3 discusses the effect of caregiver burden on nursing home placement. Chapter 4 focuses on changes in structural attributes of the informal helper network, and tests a model of the effect of caregiver burden on this change. Chapter 5 focuses on effect of caregiver burden on changes in use of formal helpers. Chapter 6 examines the effect of burden on hospitalization and volume of hospital service. Chapter 7 summarizes and integrates our conclusions about the effect of caregiver burden on the major outcomes.

II. DESCRIPTION OF SAMPLE AND MAJOR VARIABLES

This study is based on analyses of the 1982 and 1984 waves of the National Long Tenn Care Surveys (NLTCS), including the Informal Caregivers Survey component which was collected in 1982 only. The major purpose was to investigate the impact of family caregiver burden on risk of admission to nursing homes, use of hospitals, and stability of family care. The definition of the specific sample shifted somewhat in relations to each research question; thus, careful attention must be paid to the sample descriptions of each analysis. For example, the analysis of the impact of caregiver burden on nursing home admission compared continuous community residents to those institutionalized between 1982 and 1984; this latter group includes those residing in institutions at the time of data collection in 1984,those who entered a nursing home and subsequently died before 1984, and a few who returned to the community. By contrast, analyses of the impact of caregiver burden on caregiver stability used a longitudinal sample of community residents in both 1982 and 1984.

Sample

The data are drawn from the 1982-1984 National Long Term Care Survey (LTCS) and a companion Informal Caregivers Survey. The National Long Term Care Survey of frail older persons investigated the demographic characteristics, health and functioning, and patterns of assistance of a national sample of non-institutionalized persons 65 years of age or over. A random sample of approximately 36,000 persons drawn from Medicare enrollment files were screened to identify persons with functional limitations, defined as inability to perform at least one activity of personal care or management of daily affairs for a period of 3 months or more. In 1982, over 6400 persons were identified and 6,393 persons (95.3 percent response rate) were interviewed. Twenty-six percent of these interviews were conducted with proxies who were knowledgeable about the elder person's health care needs. The 1984 survey includes longitudinal followup of respondents still living in the community (n=4,530) and specialized questionnaires for respondents living in nursing homes (n=1071), and for the next of kin of deceased subjects (n=2475). Of the 6393 community disabled identified in 1982, 21.6 percent died, 7.6 percent were institutionalized, 6 percent were no longer disabled, and 64 percent continued to be community-dwelling functionally disabled (Manton and Liu, 1987). (See Macken, 1986, for detailed discussion of sampling procedures and methodology of the 1982 surveys and Manton, 1988 for detailed discussion of the 1984 survey methodology.)

The Informal Caregivers Survey was conducted by the National Opinion Research Center in 1983 on the sub-population of informal helpers, 14 years or older, who were identified by a random sample of the LTCS respondents. To be eligible for selection, helpers had to provide activity of daily living (ADL) assistance. Multiple caregivers for a frail older person were eligible for interviews. Of the 2,369 selected eligible caregivers, 280 were ineligible for technical reasons, 307 were no longer providing care, and 165 refused to participate, resulting in completed interviews with 1617 active caregivers. (See Stone et al., 1987 for detailed discussion of sampling procedures and methodology.) The caregiver survey was not repeated in 1984.

The sample analyzed in this study was further restricted to focus on a subset of older persons who had sole spouse and adult child caregivers in 1982. One of our initial task was to assess the extent to which descriptions of caregivers or helpers in 1982 could be matched to those in 1984. We thus selected our study sample to represent older persons who received care from immediate family members, assuming that this group of caregivers would be most likely to be reported as helpers in the elder interview at each time point. Specific analysis of the probable match between this subsample of caregivers and helper characteristics suggested that all of the spouses in the caregiver sample matched spouse information in the elder survey; some discrepancy in exact match of identifying characteristics was observed in 25 cases in which the primary caregiver was an adult child. These cases were retained in the analysis.

The result is a 1982 base sample of 940 caregivers thus included 351 wives (37 percent), 203 husbands (21.6 percent), 304 daughters (32.3 percent) and 82 sons (8.7 percent) and the frail older persons they assisted. In 1984, 644 older persons from this subsample were still living in the community and form the basis for most of the longitudinal analyses.

The criteria for defining the subpopulation created divergences with characteristics of the total caregiver sample and the total older person sample. Relative to the total caregiver survey, the study sample of caregivers contains a higher proportion of spouses, largely due to our exclusion of elders with multiple caregivers (Table 2-1). This subsample also contains slightly more males and more white caregivers. In addition, the sampled caregivers are more likely to live with the frail older person than the total sample of caregivers. Differences between attributes of the subsample in 1982 and those remaining in the community in 1984 are minimal, suggesting that death and institutionalization rates did not vary greatly by caregiver characteristic.

Our study sample of frail older persons also differs from the total community 1982 frail elder sample (Table 2-2). The frail elderly in our 1982 subsample of 940 are somewhat older, more likely to be married, and appear to be more functionally impaired. As a result of differential institutionalization and death rates, the 1984 longitudinal community sample (n=644) has a higher proportion of elders with 0-1 ADL limitations than the 1982 distribution.

We took account of the complex sampling design only in producing initial estimates of the distribution of the key variables in the population of frail older persons. We used the weights provided by NORC which take into account the probability of selection of both the older subject and the informal caregiver.

Measurement of Key Variables

This section provides the conceptual and operational definitions of major study variables. Selected measurement issues will be discussed in the relevant context of the analytic chapters. Table 2-3 lists the major independent and dependent variables and their source.

Dependent Variables:

We examined two service related outcomes (nursing home admission and hospital use), and, one informal care outcome (stability of family caregiving). *Hospital use* was measured by three indicators: whether or not a patient was ever admitted to the hospital within the past 12 months, the number of hospital admissions in the past 12 months, and total days of hospitalization up to three admissions. *Nursing home use* was measured as admission to a nursing home between the 1982 and 1984 interviews. Subjects were classified as having a nursing home admission if they had one or more stays in a nursing home between the 1982 and 1984 interviews. Deceased subjects were classified as admissions if they died in a nursing home, had been living in a nursing home just before death, or had a nursing home stay between the 1982 and 1984 interviews. Sources of information included the 1984 community and institutional surveys and the 1984 survey of next of kin of deceased subjects.

Caregiver stability was conceptualized as a network attribute of the frail older person. Network ties were defined on the basis of structural links rather than interactional levels. We examined three structural dimensions of informal instrumental task support: availability of helpers indicated by the number of people in the elder's household; number of informal helpers identified by the older person who assist with at least one ADL and/or IADL activity; and amount of informal help provided measured by the sum of the days of help provided by all informal helpers of a specific elder. We also examined two dimensions of formal support: the number of formal helpers (paid helpers or persons from an organization who provide ADL or IADL assistance), and amount of formal help provided measured by the sum of the days of help provided by all formal helpers of a specific elder.

Independent Variables.

The independent variables can be categorized as sociodemographic characteristics of elders and caregivers, elder health and functional status 1982 and 1984, level of caregiver involvement, and caregiver burden. Measurement of many of these variables are straightforward, but we provide extensive descriptions of composite scales and measures of specialized concepts. Sociodemographic characteristics coded as dichotomous variables include gender (1=female), race 0=white), relationship of caregiver (0=spouse, 1=adult child), and marital status (1=married).

Functional status in 1982 and 1984 is measured by the number of ADL and IADL limitations for which help was received in the previous week. For each Activity of Daily Living, e.g., bathing, we created a dichotomous measure of need which was then summed. ADL limitation was assessed by the presence of personal help with or without use of special equipment, special equipment only, or total dependency. Assistance via supervision alone was not defined as a limitations as we believed such judgments are ambiguous in the situation of family caregiving. The ADL limitations included were the older person's need of help with eating, dressing, bathing, bed transfers, mobility, and toileting (range 0-6). Instrumental Activities of Daily Living (IADL) were measured in a comparable fashion, with IADL need defined by inability to perform IADL task because of a health problem or disability. The IADL tasks included are heavy household work, light household work, laundry, meal preparation, shopping, mobility outside of house, transportation, money management, taking medications, and use of the telephone (0-10). Individuals who did not get out of bed or move around inside were defined automatically as having limitations on all IADLs excluding financial management, taking medications, and use of telephone. These three items were measured directly. Functional status measures were recoded, based on examination of the frequency distributions for use as categorical measures in selected analyses. ADI limitations were coded as mild (0), moderate (1,2) or severe (3-6); IADL limitations were coded as mild (0-3), moderate (4-7), or severe (8-10).

A second measure of the older person's health status was the number of categories of chronic conditions (range 0-7). We first created, then summed seven categories of chronic conditions: arthritis (arthritis/rheumatism), cancer, diabetes, infirmities (broken hip, other bone fractures, permanent stiffness), nervous system (paralysis, multiple sclerosis, cerebral palsy, epilepsy nd Parkinson's disease), circulatory (heart attack, artereosclorosis, high blood pressure, other heart problems, stroke, etc), and respiratory (pneumonia, emphysema, asthma). This index was highly related to a count of number of chronic conditions (r=,82) in 1982, but was less strongly influenced by the many circulatory conditions assessed. In the longitudinal sample, the correlation of number of chronic condition categories correlated moderately well with self-rated health (r=.33), number of ADL limitations (r=.30), and number of IADL limitations (r=.28).

Mental status was measured by the number of errors on the Short Portable Mental Status Examination (Pfeiffer, 1975). These questions were not asked of elders too ill to respond and thus missing data became a serious validity issue. We dealt with this issue in two ways. First, in some analyses we used the measure of whether a proxy respondent was used. In other analyses, we substituted the mean value for those with proxy respondents and concluded a second dummy variable for presence of the proxy. These two variables were used and interpreted in tandem. The cognitive status measure thus represents the effect of cognitive status for those responding and the proxy measure reflects the differential impact of having a proxy versus self report. The proxy measure represents the respondent with the most severe mental impairment with severe functional disability, an analysis of subjects with proxys in the National

Channelling study suggests they reflect many of the attributes of those with severe cognitive impairments (Coughlin and Liu, 1989).

Our assessment of income was based primarily on summary items of family income in 1982 and 1984 (sixteen categories coded from 1=less than $3,000 to 16 = over $50,000). These items has approximately 15 percent missing data. Analysis of patterns of missing data showed that missing data was more common in females, the unmarried, those with primary child caregivers, and those living with nonrelatives or with relatives who were not the spouse or an adult child. We developed regression models to explain income in those with complete data. The models contained variables related to individual incomes (race, sex, age, size of place of residence). In addition, variables were included to represent possible differentials in reporting patterns, such as whether a proxy respondent was used for most of the interview. Finally, two variables assessing income patterns related to living situation were included: whether the subject lives with a spouse, and whether the subject lives with a child. This group of variables explained 24 percent of the variance (R2) in the 785 cases with complete data. Family income in 1982 was significantly related to race, place of residence, household size, living with a spouse, living with a child, and marital status. Family income in 1984 was regressed on the same set of variables measured in 1984. The variables explained 26 percent of the variance in the 489 cases with complete data. The 1984 analyses identified a similar set of predictors: place of residence, race, number in household, living with a child, and marital status. The two regression equations were used to create predicted values of family income in cases with missing data. Income is thus based on reported income for those responding to the question and imputed values for those with missing data. Income was also normed by the number in the household to provide a measure of per capita income.

Caregiver Burden was assessed by summing a series of dichotomous questions that asked about problems experienced as a result of caregiving. These items are similar to those in other burden inventories (Robinson, 1983; Zarit et al., 1980). Ten items formed two dimensions of burden. The Personal burden scale is comprised of six items: worsening health; cost of care more than could afford; need to take care when not well; emotional strains; limitations on social activities; and elder needs constant attention. This scale reflects the caregiver's appraisal of limitations in personal actions and activities as a result of providing care, and in many respects reflects the confinement associated with intense care of an disabled person. The Interpersonal burden scale is limited to the caregiver's perception of difficult elder behaviors: forgetting things; embarrassing caregiver; lapsing into senility; becoming upset and yelling. Interpersonal burden represents the caregiver's appraisal of selected interpersonal difficulties that disturb established relationship patterns with the dependent care-receiver, and thus reflects both attributes of the care-receiver, e.g. yelling behaviors, and the reaction of the caregiver, e.g. defining it as a problem. Although these behaviors are similar to those exhibited by older persons with cognitive impairments, such behaviors occur in other contexts as well.

Table 2-4 presents the frequencies distribution of the component variables. The most frequently mentioned problems associated with personal burden were experiencing limitations in social and personal activities, emotional strain, and having to provide care when not feeling well. The most frequently mentioned problems in interpersonal burden was the older person's forgetting things and yelling or becoming upset. The additive versions of these scales have internal reliabilities (Chronbach's Alpha) of .76 for Personal burden and .68 for Interpersonal burden. Chapter 4 presents the results of a confirmatory factor analyses which further corroborates this two-dimensional model.

Table 2-5 presents the means scores of personal and interpersonal burden by selected caregiver and frail older person characteristics in 1982. These relationships provide the context within which the effects of burden on long term care outcomes will be analyzed. Significantly greater personal burden is reported by female caregivers caring for frail persons with moderate per capita family income, and who have severe ADL and IADL limitations. Greater interpersonal burden is reported by female and adult child caregivers who are caring for older frail persons who have severe ADL and IADL limitations. Both personal and interpersonal burden share significant associations with functional limitations, but differ somewhat in their relationships with other caregiver and frail elder socio-demographic characteristics.

Descriptive Findings

To complete the discussion of the sample and measures, we present a series of tables of characteristics of the frail elder in 1982 and 1984. Table 2-6 compares the 1982 sample with the 1984 sample remaining in the community and shows relatively little change in distributions of each variable, except for the slightly higher proportion of females in 1984. Table 2-7 indicates the distribution of number of ADL limitations for 1982 and 1984. The distributions are markedly different. Possibly as a result of differential mortality rates, the survivors in 1984 have a greater proportion in the 0-1 ADL category than in 1982. The transition table presented in Table 2-8 gives some clues to the effect of mortality on the transitions and also details the patterns of improvement and decline over the two year period by subgroup. The transition to mortality among males with few ADL limitations in 1982 is particularly marked when contrasted with the lower mortality rates of females with high ADL limitations in 1982. Given the greater likelihood for adult women to care for female elders, this differential mortality may account for the similar pattern of stability and change among older persons with adult child caregivers. Also intriguing are the sizeable proportion of those who improved in ADL status during the two-year period.

Table 2-9, Table 2-10, and Table 2-11 compare the distributions of our major dependent variables. There appears to be a only a slight overall decline in percent hospitalized and mean days of hospitalization from 1982 to 1984 (Table 2-9), reflecting perhaps, the full implementation of prospective reimbursement system and its accompanying decreases in average length of stay during this period. In our sample, the shifts in distributions are most marked in comparisons within race and within caregiver relationship. The 1982 differential between percent white and non-white hospitalized was minimal in 1984 because of increase in hospitalization by non-whites. Older persons cared for by adult children were less likely to be hospitalized in 1984 than were impaired partners of caregiving spouses.

We see only a slight shift in the mean number of informal and total number of helpers between 1982 and 1984 (Table 2-10). In Table 2-11, we describe the outcomes of mortality and institutionalization by demographic characteristics. Among males, there was a greater likelihood of mortality and less likelihood of nursing home placement than among females. Nursing home utilization by non-whites was minimal. Outcomes by caregiver relationship suggest that although there was little difference in mortality rates by caregiver relationship, older persons cared for by adult children were twice as likely to be institutionalized as those cared for by spouses. Lastly, a strong gradient effect between nursing home institutionalization and placement exists for ADL status in 1982, but not for self-rated health.

TABLE 2-1. Characteristics of Caregiver Sample, 1982

Caregiver Characteristics	Baseline Sample (N=940)	Community Sample (N=644)	Total Sample[1] (N=1,924)
AGE IN YEARS			
14-44	6.6	6.8	21.6
45-64	39.2	38.4	41.4
65-74	34.9	36.5	25.4
75+	19.3	18.3	10.1
SEX			
Male	30.3	33.1	28.5
Female	69.7	66.9	71.5
RELATIONSHIP			
Spouse	58.9	60.4	35.5
Adult child	41.1	39.6	37.4
Other	a	a	27.1
RACE			
White	87.2	86.6	79.5
Other	12.8	13.4	20.5
LIVE WITH ELDER			
No	11.1	10.2	26.1
Yes	88.9	89.8	73.9

NOTES:
1. SOURCE: Stone, R., Cafferata, G. and Sangl, J. 1987. Caregivers of the frail elderly: A national profile. The Gerontologist, 27, 616-626.

a. Subsample selected only spouses and adult child caregivers.

TABLE 2-2. Sample Characteristics of Frail Elders, 1982-84

Elder Characteristics	1982			1984		
	NLTCS[1]	Subsample n=940	Community n=644	Community n=644	Nursing Home n=68	Died n=228
AGE						
65-69	32.6	19.4	21.7	13.0*	8.8	15.8
70-74	26.5	24.7	24.7	24.5	13.2	21.1
75-79	19.1	19.4	18.9	21.1	16.2	21.5
80-85	12.0	17.7	16.3	17.2	30.9	17.5
85+	9.9	20.6	18.3	24.1	30.9	24.1
SEX						
Male	40.1	43.1	39.6	39.2	33.8	55.7
Female	59.9	56.9	60.4	60.4	66.2	44.3
MARITAL STATUS						
Married	43.5	62.6	63.7	61.5*	45.6	64.8
Widowed	46.8	34.8	34.3	36.4	52.9	30.8
Divorced/ Separated	4.7	2.2	1.5	1.4	1.5	4.4
Never married	4.9	.3	.5	.7	0.0	0.0
RACE						
White	88.2	87.9	87.3	87.3	98.5	86.4
Other	8.9	12.1	12.7	12.7	1.5	13.6
ADL LIMITATIONS						
0-1	56.0	31.3	33.7	42.9*	23.5	26.8
2-3	24.7	31.9	33.7	24.4	27.9	28.1
4-6	19.3	36.8	32.6	32.8	48.5	45.2

* Percentages in these categories represent the distribution by 1984 variable status, e.g. age category, marital status, and ADL status in 1984.

1. SOURCE: Macken, C. A Profile of functionally impaired elderly persons living in the community. Health Care Financing Review 7: 51-58.

TABLE 2-3. Description and Source of Variables	
Variables	**Data Source**
SOCIODEMOGRAPHIC, ELDER AND CAREGIVER	
Age, Sex, Family Income, Education Living Arrangement, Caregiver Relation to Elder	1982 Community Survey, 1982 Caregiver Survey
ELDER HEALTH STATUS	
Functional status ADL assistance (6 ADL items) IADL assistance (10 IADL items)	1982 & 1984 Community Survey
Mental Status	
Health Status (overall assessment and chronic conditions)	1982 & 1984 Community Survey
CAREGIVER SURVEY	
Personal Burden (e.g., limitations in activities, costs of care)	1982 Caregiver Survey
Interpersonal Burden (e.g. elder forgets things, embarrasses caregiver)	1982 Caregiver Survey
HOSPITAL USE	
Hospitalized in past 12 months	1982 & 1984 Community Survey
Number of hospitalizations	
Average length of stay	
NURSING HOME ADMISSION	1984 Community Survey 1984 Institutionalized/ deceased Surveys
HELPER NETWORK STABILITY	
Number in household	1982, 1984 Community Surveys
Number of informal helpers	
Informal person days of help	
Use of formal services	
Formal person days of help	
Composition of helper network	

TABLE 2-4. Frequency Distribution of Indicators of Burden. (N=940)		
	Presence of Problem	
	N	**%**
PERSONAL BURDEN		
Problem with:		
Social limitations	487	51.8
Constant attention	324	34.5
Worsening health	181	19.3
Costs more than can afford	204	21.7
Gives care when not well	415	44.1
Emotional strain	429	45.6
INTERPERSONAL BURDEN		
Problems with older person:		
Forgetting things	556	59.1
Embarassing behavior	201	21.4
Senile lapses	235	25.0
Yelling and becoming upset	386	39.1

TABLE 2-5. Mean Burden Scores by Selected Caregiver and Older Person Characteristics

	Personal Burden		Interpersonal Burden	
	Mean	**St. Deviation**	**Mean**	**St. Deviation**
CAREGIVER CHARACTERISTICS				
SEX				
Male	1.77	1.83***	1.17	1.20***
Female	2.34	1.87	1.57	1.33
RACE				
Nonwhite	2.14	1.72	1.61	1.33
White	2.17	1.90	1.42	1.30
RELATIONSHIP				
Spouse	2.20	1.93	1.34	1.29**
Adult child	2.12	1.80	1.60	1.31
OLDER PERSON CHARACTERISTICS				
AGE				
65-69	2.18	1.88*	1.20	1.21***
70-74	1.92	1.82	1.24	1.24
75-79	2.05	1.83	1.48	1.34
80-84	2.34	1.80	1.73	1.36
85+	2.43	2.02	1.63	1.31
PER CAPITA FAMILY INCOME				
Low	2.11	1.86*	1.47	1.28
Medium	2.39	1.93	1.50	1.35
High	2.03	1.84	1.39	1.29
ADL LIMITATIONS				
Mild (0-1)	1.66	1.67***	1.29	1.23*
Moderate	1.96	1.90	1.42	1.28
Severe	2.79	1.86	1.60	1.37
IADL LIMITATIONS				
Mild (0-3)	1.22	1.53***	1.04	1.16***
Moderate (4-7)	1.94	1.74	1.35	1.25
Severe (8-10)	2.93	1.90	1.77	1.37

* =Probability of F- value < .05
** =Probability of F- value < .01
*** =Probability of F- value < .001

TABLE 2-6. Selected Demographic Characteristics of Frail Elders of Family Caregivers, 1982-1984. (weighted)				
	1982		1984	
	Number	Percent	Number	Percent
AGE				
65-69	222,071	21.0	99,498	13.7
70-74	234,454	22.2	181,563	25.0
75-79	197,241	18.6	150,825	20.7
80-84	188,706	17.8	122,413	16.8
85+	215,267	20.4	173,232	23.8
SEX				
Male	457,838	43.3	288,018	39.6
Female	599,900	56.7	439,513	60.4
RACE				
White	923,102	87.3	629,339	86.5
Nonwhite	134,636	12.7	98,192	13.5
EDUCATIONAL STATUS				
Less than high school	528,735	51.7	357,700	54.7
H.S.graduate	358,522	35.0	84,209	12.8
Higher than high school	136,083	13.3	214,096	32.6
MARITAL STATUS				
Married	391,402	37.1	265,815	38.6
Not married	666,802	62.9	422,152	62.4
CARE RELATIONSHIP				
Spouse	624,900	59.1	436,767	60.0
Adult child	432,838	40.9	290,763	40.0
TOTAL	1,057,738		727,531	

TABLE 2-7. Number of Basic ADL's by Age, Sex, Race and Family Relationship 1982-1984. (N=940)							
	Number of ADL's						
	1982			1984			
	0-1	2-3	4-6	0-1	2-3	4-6	Deceased
AGE							
65-69 years	30.2	36.3	33.5	39.8	23.1	17.6	19.4
70-74	41.7	25.9	32.4	41.6	17.3	22.8	18.3
75-79	29.1	30.2	40.7	36.0	12.8	23.6	27.6
80-84	28.9	30.7	40.4	38.3	13.8	24.0	24.0
85+	24.7	37.1	38.1	30.8	18.5	22.3	28.5
SEX							
Male	36.0	30.1	33.8	33.6	14.6	20.5	31.4
Female	27.7	33.3	39.1	38.9	18.3	23.9	18.9
RACE							
White	31.6	31.5	36.9	27.8	16.0	22.4	23.8
Other	28.9	35.1	36.0	28.1	21.9	22.8	27.2
RELATIONSHIP							
Spouse	32.3	31.9	35.7	36.1	16.2	22.9	24.7
Adult child	29.8	31.9	38.3	37.3	17.4	21.8	23.6
TOTAL	31.3	31.9	36.8	36.6	16.7	22.4	24.3
N	294	300	346	344	157	211	228

TABLE 2-8. Number of Basic ADL's by Age, Sex, Race and Family Relationship 1982-1984 (N=940)

1984 ADL	1982 0-1 ADL				1982 2-3 ADL				1982 4-6 ADL			
	0-1	**2-3**	**4-6**	**Dec.**	**0-1**	**2-3**	**4-6**	**Dec.**	**0-1**	**2-3**	**4-6**	**Dec.**
AGE												
65-69	63.6	9.1	5.5	21.8	39.4	31.8	15.2	13.6	19.7	14.8	41.0	24.6
70-74	63.3	13.3	7.8	15.6	26.8	26.8	26.8	19.6	25.7	8.6	32.9	32.9
75-79	56.6	7.5	7.5	28.3	32.7	27.3	20.0	20.0	17.6	10.8	40.5	31.1
80-84	58.3	12.5	6.3	22.9	47.1	13.7	19.6	19.6	22.4	13.4	35.8	47.5
85+	56.3	14.6	10.4	18.8	18.1	34.7	15.3	31.9	17.6	10.8	40.5	31.1
SEX												
Male	48.6	13.0	7.5	30.8	31.1	24.6	19.7	24.6	19.7	7.3	35.0	38.0
Female	71.6	10.1	7.4	10.8	32.6	29.8	18.5	19.1	21.1	14.4	40.2	24.4
RACE												
White	59.8	11.9	2.7	20.7	35.0	25.8	18.8	20.4	21.3	11.1	38.0	29.5
Other	63.6	9.1	6.1	21.2	12.5	40.0	20.0	27.5	14.6	14.6	39.0	31.7
RELATIONSHIP												
Spouse	55.9	12.8	7.8	23.5	33.3	26.6	20.3	19.8	20.7	10.1	38.9	30.3
Adult child	67.0	9.6	7.0	16.5	30.1	29.3	17.1	23.6	20.3	13.5	37.2	29.1
TOTAL	18.8	3.6	2.3	6.5	10.2	8.8	6.1	6.8	7.6	4.3	14.0	11.0
N =	177	34	22	61	96	83	57	64	71	40	132	103

TABLE 2-9. Hospital Use and Days of Hospitalization by Age, Sex, Race, and Family Relationship, 1982-1984.

	1982			1984		
	Hospital Use	**Days in Hospital**		**Hospital Use**	**Days in Hospital**	
	Percent	**Mean**	**St. Dev.**	**Percent**	**Mean**	**St. Dev.**
AGE						
65-69	37.1	23.35	28.44	44.9	16.66	27.34
70-74	44.0	24.62	26.65	34.4	20.90	31.41
75-79	44.3	20.13	20.91	45.7	16.10	23.01
80-85	40.0	18.71	12.72	33.0	18.56	21.89
85+	30.5	17.75	23.54	34.5	12.90	11.49
SEX						
Male	39.6	23.46	27.18	39.9	18.70	26.85
Female	39.3	20.11	20.91	36.6	15.65	21.45
RACE						
White	40.4	20.85	23.08	37.5	16.47	23.24
Other	32.9	26.37	27.71	38.0	20.07	27.94
RELATIONSHIP						
Spouse	40.2	22.20	25.98	41.5	17.30	24.51
Adult child	38.2	20.23	19.28	32.5	16.22	22.69
TOTAL	39.4			37.8		
N	642	253		606	230	

TABLE 2-10. Mean Number of Informal and Formal Helpers by Age, Sex, Race and Family Relationship 1982-1984. (N=615)

	1982		1984	
	Informal Helpers	**Formal Helpers**	**Informal Helpers**	**Formal Helpers**
AGE				
65-69 years	1.44 (.89)	.13 (.44)	1.57 (1.01)	.21 (.57)
70-74	1.56 (.99)	.18 (.49)	1.55 (1.05)	.28 (.62)
75-79	1.66 (1.00)	.23 (.53)	1.87 (1.30)	.48 (.75)
80-84	2.07 (1.12)	.19 (.44)	1.96 (1.35)	.51 (.88)
85+	1.87 (1.08)	.26 (.51)	2.03 (1.09)	.46 (.68)
SEX				
Male	1.47 (.91)	.13 (.42)	1.71 (1.20)	.33 (.70)
Female	1.84 (1.08)	.24 (.52)	1.81 (1.14)	.40 (.70)
RACE				
White	1.66 (1.01)	.18 (.46)	1.72 (1.15)	.37 (.70)
Nonwhite	1.91 (1.15)	.27 (.63)	2.09 (1.24)	.37 (.73)
RELATIONSHIP				
Spouse	1.44 (.85)	.17 (.45)	1.60 (1.15)	.36 (.72)
Adult child	2.08 (1.16)	.23 (.54)	2.02 (1.14)	.39 (.67)

NOTE: Standard deviations are in parentheses.

TABLE 2-11. Status in 1984 by Selected Variables. (N=940)

	Community Residents (N=619)	**Nursing Home Residents (N=68)**	**Deceased (n=219)**
AGE IN 1982			
65-69	76.9	3.3	19.8
70-74	73.6	4.2	22.2
75-79	67.0	6.0	26.9
80-84	63.3	12.7	24.1
85+	60.8	10.8	28.4
SEX			
Male	63.0	5.7	31.4
Female	72.7	8.4	18.9
RACE			
White	68.0	8.1	23.8
Nonwhite	71.9	.9	27.2
RELATIONSHIP			
Spouse	70.2	5.1	24.7
Child	66.1	10.4	23.6
ADL 1982			
0-1	73.8	5.4	20.7
2-3	72.3	6.3	21.3
4-6	60.7	9.5	29.8
TOTAL			
Percent	68.5	7.2	24.3
Number	644	68	228

III. THE EFFECT OF CAREGIVER BURDEN ON INSTITUTIONALIZATION

A common assumption of policy makers and gerontological research is that caregiver burden increases the vulnerability of disabled elders to nursing home placement (Stephens and Christianson, 1986). Two streams of research, family decision- making, and epidemiological predictors of risk of institutionalization, contribute mixed evidence for this assumption. The two streams rarely intersect, although studies of risk of institutionalization have generally shown the importance of ongoing social support in continued community residence in the face of disability.

Studies of the process of family decision-making in relation to the institutionalization of a family member emphasizes the importance of decline in the functioning of the older person, and changes in the social situation of the elder and/or of the caregivers. Deirnling and Poulshock (1985) have pointed to the importance of the negative effect of caregiving on the mental and physical health of the caregiver to the decision to institutionalize. While decline in elder's health was reported as the most important reason by 68 percent of relatives of applicants for nursing home care, change in the informal support system or a reduced capacity for caregiving was the most important reason by 20 percent and the second most important reason by 28 percent (Arling and McAuley, 1983).

The relative role of elder and caregiver characteristics may vary by relationship and the type of disability. While not examining the outcome of institutionalization, Cantor (1983) suggests that strain and involvement is greater in more intimate relationships such as among spouses. Spouse caregivers, however, tend to sustain the caregiving role longer than other relatives (Colerick and George, 1986). This study of caregivers of Alzheimer's disease patients found caregiver well-being and need for help more influential in institutionalization than severity of symptoms or duration of illness (Colerick and George, 1986). It is possible that the particularly difficult nature of caregiving for demented elderly increases the importance of caregiver resources in the decision to institutionalize when compared to similar decisions made by families of elders with primarily physical disabilities.

The decision to institutionalize family members is a difficult one (Townsend, 1988), increasingly so because the decision is often triggered by crisis. Studies of the institutionalization decision have used retrospective interviews e.g., Deimling and Poulshock (1985), or to a lesser extent, interviews at the time of application (Arling and McAuley, 1985). In considering the possible effect of the timing of interviews on the reasons for placement given by relatives, we must consider the emotional stress of the placement decision and the low regard with which nursing homes are viewed. Thus, these reported reasons may represent explanations that relatives think best justify the decision to place a family member in a nursing home.

To understand the role of caregiver burden in the decision to institutionalize, it is preferable to assess the problems faced by caregivers in advance of the crisis-like moment of decision-making or separate from the organizing accounts justifying an admittedly difficult decision. Thus, despite the instructiveness of these studies of caregiver burden and of family decision-making, they present numerous methodological difficulties. In addition to the difficulties of dealing with retrospective reports, the studies tend to be small, geographically unrepresentative, and based on a narrow range of patient problems, factors which hamper the ability to generalize. A separate but related body of epidemiological literature has concentrated on demographic and clinical indicators of risk of entering a nursing home, being a resident of a nursing home, or the volume of nursing home care. These studies have a relatively high degree of convergence in results. This convergence is notable in light of differences in the populations examined, e.g., hospitalized patients (Kane et al., 1983), participants in a home care programs (Hughes et al., 1987), Medicare beneficiaries (Cohen et al., 1986), and in the different time intervals examined, ranging from one year (Cohen et al., 1986) to six years (Branch and Jette, 1982).

In this chapter, we have categorized risk factors as related to elder sociodemographics, health and functioning, and the caregiving context. Risk is generally higher among those with advanced age, particularly above 85 years of age (e.g., Kane et al., 1983; Hughes et al., 1987; Shapiro and Tate, 1988). This pattern was also supported by Cohen et al. (1986) who used a quadratic function to represent the heightened impact of extreme age. The studies reviewed did not report race as a risk factor although nursing home residents are more likely to be white (Hing, 1987). Studies of nursing home residents report much higher rates of women (Hing, 1987), but gender is a less consistently reported factor in studies of admission. For example, Kane et al. (1983) report women more likely to be placed in nursing homes following hospitalization, but gender was not a factor in admission in a prospective study of community residents (Branch and Jette, 1982). In considering the role of these sociodemographic factors, we must take into account both differential exposure to disability and mortality and the associated differences in patterns of social support available to members of different demographic categories.

Health and functional status variables are also associated with differential risk of admission. Severe functional disability predicts nursing home admission in all studies reviewed. In addition, cognitive problems were found to be significant risk factors in most studies. While such a high degree of convergence is notable in social and clinical research, there is considerable divergence with respect to the indices of key concepts included in models. For example, functional limitations may be assessed as one or more Activity of Daily Living (ADL) limitation (Shapiro and Tate, 1988; Branch and Jette, 1982), by a particular ADL such as dependence in bathing (Hughes et al., 1987). Others include measures such as needing help getting around or being confined to bed (Cohen et al., 1986) or having limitations in instrumental Activities of Daily Living (IADL) (Branch and Jette, 1982). There is also variation in assessment of cognitive impairment ranging from simple interviewer assessments of degree of orientation (Branch and Jette, 1982) or ability to comprehend (Shapiro and Tate, 1982), to diagnosis of mental disorder (Kane et al., 1983), to screening instruments such as the Short Portable Mental Status Questionnaire (Hughes et al., 1987).

Studies of the risk of admission confirm, in general, the importance of lack of social support in nursing home placement. Many studies have identified the importance of marital status, pointing to the heightened risk of widowhood (Cohen et al., 1986) or more generally not being married (Hughes et al., 1987; Shapiro and Tate, 1988). Living alone, which is associated with marital status, was identified as a risk factor in additional studies (e.g., Branch and Jette, 1982). Studies which evaluate the impact of home care and case management services on use of nursing homes have relevance. Hughes et al. (1987) reported that participation in a home care service program was associated with lower risk of nursing home admission. The National Long Term Care Demonstration reported no significant reduction in admission (Wooldridge and Schore, 198?). We should note that assessment of social supports has not received the same care as that of functional limitations, and that conclusions concerning the importance of social support have been based on single item measures of sociodemographic characteristics, rather than detailed assessment of support networks.

While studies of family decision-making have tended to focus on family caregiver's reasons for placement to the exclusion of reports from the frail elder, studies of predictors of admission or nursing home residence have lacked information from the caregiver or family members. In particular, they have lacked detailed information from the perspective of caregivers.

This chapter reports data from integrated surveys of caregivers and disabled elderly. We assess the role of dimensions of caregiver burden on the risk of admission to a nursing home between 1982 and 1984, controlling for level of functioning, sociodemographic characteristics, and aspects of the context of care. The purpose of the analyses is to examine the role of two forms of caregiver burden on risk of institutionalization, controlling for variables identified as influential in nursing home placement.

Sample and Methods

A subject was classified as a nursing home admission if the admission occurred between 1982 and 1984, resulting in 127 admissions or an admission rate of 17 percent. At the time of the 1984 interview, 18 (14 percent) were community residents, 68 (54 percent) were nursing home residents, and 41 (32 percent) were deceased. The comparison group consisted of 626 continuous community residents.

The predictor variables examined are divided into three categories. First, elder characteristics include sex, race, age, and whether the subject lived with others. Second, functional status variables included cognitive status and whether a proxy was used for the cognitive items, Activities of Daily Living (ADL), and Instrumental Activities of Daily Living (IADL). Third, variables assessing the context of caregiving included relationship of primary caregiver, number of informal helpers, use of paid help or formal services, interpersonal burden, and personal burden. Marital status was not included in the model because of its high association with relationship of primary caregiver. These variables are described in detail in Chapter Two.

Plan of Analysis

We first examined the bivariate relationship of the three sets of variables on nursing home admission. Second, we performed multivariate analyses of occurrence of nursing home admission compared to elders remaining continuously in the community. Multiple logistic regression was used for the multivariate analyses.

One methodological issue raised by our review of the literature was the strong risk of instability in estimates. In our review of prior studies, we noted that analysts frequently tested the effects of large numbers of variables relative to the number of admissions and that the variables examined appeared likely to be collinear. In logistic regression, the size of the group predicted, in this case, the number of admissions, places stronger limitations on the number of risk factors that can be examined without leading to instability than does the total sample size. In our study we have attempted to adhere to a rule of thumb of 10 cases per predictor. While many of the studies reviewed began with large samples, few had more than 150 admissions, but have frequently tested many risk factors, leading to risk of unstable estimates. Instability is more likely with collinear sets of predictors as well. We find collinearity to be an issue in predicting nursing home admission, and have conducted detailed analyses to assess collinearity and to assess the effects of sets of possibly collinear variables.

Results

Bivariate analyses showed that the nursing home admissions differed from continuous community residents in many respects. Table 3.1 summarizes group means and two-sample t-tests for the three sets of variables. In presenting t-values, we have assessed the homogeneity of variances and presented calculations appropriate for heterogeneous variances where appropriate. Among elder characteristics, patients admitted to nursing homes had higher mean age and were more likely to be white. Sex and whether the elder lived with others was not found to distinguish the two groups. Gender has been less consistently found to be a factor in nursing home admission than has some of the other demographic characteristics, although the preponderance of females in studies of nursing home residents is well known. Living alone was also not influential in risk of admission. This sample, characterized by having a spouse or adult child primary caregiver, has extremely low rates of persons living alone.

Each measure of functional status distinguished nursing home entrants from continuous community residents. Those entering a nursing home appear more distinguishable from disabled community residents with respect to cognitive indicators and IADLs than with respect to ADLs.

With the exception of number of informal helpers in 1982, all caregiver variables differed in the two groups. Relatives cared for by adult children were more likely to be admitted to nursing homes than those with a primary spouse caregiver. Use of paid help or formal assistance with ADLs and IADLs was more likely among those subsequently admitted to a nursing home prior to the 1984 interview. In addition, both interpersonal burden and personal burden were higher in caregivers of relatives later admitted to nursing homes.

Table 3.2 shows the results of a logistic regression equation predicting nursing home admission in comparison to continuous community residence. The table presents regression coefficients, and standard errors. For each of five significant predictors, the marginal probability of admission is shown. For dichotomous variables, the marginal probability is the change in probability of admission for a person with a trait, compared to a person without the trait, holding all other variables in the model at their mean value. For continuous variables, marginal probabilities were calculated with respect to two specified values, e.g., the change in probability of admission at age 80 compared to the probability at age 75. Probabilities are expressed in percents.

Two summary measures of the fit of the model are presented. First, the model accounts for approximately 14 percent of the total variance (model chi-square / total chi-square). Gamma, the second summary measure, is an ordinal measure of association between predicted probabilities and observed outcomes.

Five significant predictors of nursing home admission were identified. With respect to patient sociodemographic characteristics, nursing home admission was more likely with advanced age. Race was also a significant predictor, with the probability of admission by whites being 14.5 percent more likely than that of non-whites, holding other variables at mean levels. Living with others and sex were not related to admission.

Under the category of patient functioning, only level of IADL limitations predicted admission. The two measures of cognitive status must be interpreted in tandem. The coefficient for cognitive status represents the effect among those responding to the ten-item scale. The proxy measure then compares the impact of those not able to respond to the scale in relation to responders. Neither indicator had a significant impact on admission. In addition, number of ADLs failed to distinguish those admitted from continuous community residents.

Two variables related to caregiving context predicted admission. Use of formal services was associated with 21.1 percent higher probability of admission, holding all other variables at the mean. Finally, interpersonal burden was associated with increased risk of admission. To place this effect into context, consider that the mean score for personal burden was 1.4 problems. An increase from two problems (which is relatively close to the sample mean score) to three problems is associated with about 4 percent higher probability of admission. Because interpersonal burden measures caregiver problems with the elder forgetting things, being verbally abusive, having senile lapses, we wished to examine patterns in the correlation of estimates to see if interpersonal burden was entangled with the measures of cognitive status. This was not the case, and we thus conclude that this burden scale is assessing the quality of the caregiving relationship and not merely reflecting cognitive problems in the elder.

Examination of the correlation of estimates led to two additional conclusions, First, the estimate for interpersonal burden had a quite low correlation with those of cognitive status and use of a proxy in the cognitive measures. We conclude from this that interpersonal burden is not greatly confounded with independent measures of the elder's cognitive status.

Examination of the correlation of estimates also pointed to some degree of collinearity, most strongly among three sets of predictors. To assess the issue of collinearity between two paired predictors and admission, and to determine whether collinearity masked potentially significant predictors, we estimated models deleting one the variables in question and compared them with the baseline model. We examined two parameters in particular: 1) shifts in the beta coefficient of the remaining predictor and 2) change in the overall model chi-square. Three sets of variables were examined in this way: 1) personal burden in relation to interpersonal burden, 2) ADL in relation to IADL, and 3) sex and relationship in relation to age. In each case, the difference in model chi-square deleting the variable did not differ from that of baseline, indicating that the inclusion of these variables did not contribute to the fit of the model. In addition, the beta coefficients of the remaining variable in the pair did not greatly fluctuate. Other coefficients also remained generally stable as well, with the exception of the intercept.

Thus, we identified some degree of collinearity, in which variation may be attributed variously among one or another of a set of variables, but the effects of the variables examined were not sufficiently strong enough to significantly contribute to nursing home admission. In particular, we concluded from these analyses that personal burden is not a direct significant factor in risk of nursing home admission.

Discussion

Our findings have supported, in some respects, those of the published literature, such as the importance of race, age, and functional limitations as assessed by IADLs. Yet in other ways, our results diverge from prior research, since living alone or being cared for by an adult child rather than a spouse did not contribute to risk of nursing home admission. Part of the reason for this divergence may be that this sample represents older disabled respondents who had identifiable sources of family support.

The results of this study contribute to the debate on the importance of social factors by pointing to the predictive value of use of formal services and of at least one dimension of caregiver burden, interpersonal burden. The social support literature has increasingly noted the costs of providing support. Interpersonal burden, one of the key predictors in our model, may be viewed as one of the costs of caregiving. The contribution of interpersonal burden, but not personal burden, to admission suggests that is not the task demands of care but a decline in quality of family relationships that contributes to risk. However, the relatively high correlation between personal and interpersonal burden suggests that personal burden may play a role in institutionalization as a correlate of other predictors. In Chapter 5 we explore the role of personal burden on use and level of formal services, one of the major predictors of institutionalization.

Like other studies predicting nursing home admission, we examined the impact of attributes measured at a prior point in time. In the case of caregiver burden, we had the advantage of providing an assessment independent of the placement decision itself. While offering certain methodological advantages, this approach does not take into account changes in functional abilities or changes in caregiving capabilities that may be strongly related to the decision to enter a nursing home. With the fielding of the third wave of the NLTCS we can begin to examine the impact of changes in some of the variables (not, unfortunately, in caregiver burden) on admission risk.

TABLE 3-1. Group Means and Two-sample t-tests for Continuous Community Residents and Nursing Home Admissions.

	Total	Nursing Home Admission	Community Residents	t-Value
ELDER CHARACTERISTICS				
Sex (1=female)	.60	.60	.61	.22
Age	77.11	80.63	76.39	5.72***
Race (1=white)	.88	.95	.87	3.54***
Living Arrangement (1=live with others)	.91	.89	.92	-.98
FUNCTIONAL STATUS				
Cognitive	1.89	2.12	1.85	2.16*
Proxy (1=yes)	.40	.59	.36	4.93***
ADL	2.66	3.13	2.57	3.26**
IADL	5.98	7.27	5.72	5.78***
CAREGIVING CONTEXT				
Relationship (1=adult child)	.42	.53	.40	2.75**
Number of informal helpers	1.46	1.50	1.45	.90
Formal help	.18	.30	.15	3.37***
Interpersonal burden	1.43	2.06	1.30	6.10***
Personal burden	2.04	2.82	1.89	5.22***
N	751	127	624	

* Probability <.05
** Probability <.01
*** Probability <.001

TABLE 3-2. Logistic Regression on Nursing Home Admission in Relation to Continuous Community Residence			
Predictors	**Coefficient**	**Standard Error**	**Marginal Probability[a]**
ELDER CHARACTERISTICS			
Sex (female=1)	-.236	.268	
Age	.049**	.016	
65 to 70 years			1.8
70 to 75			2.2
75 to 80			2.7
80 to 85			3.2
85 to 90			3.8
Race (white=1)	1.487**	.487	14.5
Live With Others	-.250	.376	
FUNCTIONAL STATUS			
Cognitive Status	.070	.079	
Proxy Cognitive	.269	.250	
ADL	.025	.069	
IADL	.113*	.056	
0 to 2 limitations			1.6
2 to 4			1.9
4 to 6			2.3
6 to 8			2.7
8 to 10			3.1
CAREGIVING CONTEXT			
Personal Burden	.069	.069	
Interpersonal Burden	.287**	.095	
1 to 2 items			3.2
2 to 3			3.9
3 to 4			4.7
Relationship (Adult Child=1)	.154	.309	
Formal Help	.780**	.250	21.1
Informal Helpers	.045	.160	
INTERCEPT	-8.478	1.372	

-2 Log likelihood Ratio 583.92
Model Chi-square 91.94, 13 df
Model Chi-square / Total Chi-square = 14.5%

a. Marginal Probability is the change in probability of admission for a person with a trait, compared to a person without the trait, holding other variables in the model at their mean value. For continuous variable, it is change in the probability of admission at one value related to a second value. Marginal probabilities were calculated only for significant predictors. Probabilities are expressed in percents. probability is

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

IV. THE EFFECT OF CAREGIVER BURDEN ON STABILITY AND CHANGE IN THE INFORMAL TASK SUPPORT NETWORK OF FRAIL OLDER PERSONS

Stability of the caregiving context is most often discussed in terms of the transition between community care and nursing home placement, but shifts may also occur within the network of carers for a older person remaining in the community. Although most family care of the functionally disabled elder is provided by a primary caregiver, the role of supplementary helpers may be substantial. Two recent studies suggest that between 60 to 75 percent of frail older persons have two or more helpers in their caregiver networks (Stephens and Christianson, 1986; McKinlay and Tennstedt, 1986). Data based on total Informal Caregiver Survey reported that approximately 29 percent of the caregivers defined themselves as secondary caregivers only, and an additional 39 percent of the identified primary caregivers mentioned other informal or formal helpers (Stone et al., 1987).

The extent to which the structure of informal helping networks changes over time is unclear because of the lack of longitudinal studies. Shifts between and among informal caregivers may represent the ability of family members and non-relatives to flexibly respond to changing care needs of their frail relatives, or to compensate for changes in the life situation of informal caregivers, especially the primary caregiver. Demographic changes suggest possible shifts in the pool of available caregivers as a result of: a) continued growth of the proportion of the population that is elderly (Day, 1985); b) the rate of increase in the oldest old who are in greatest need of care (Manton and Liu, 1986); c) demands on the middle-aged caregiver (Lang and Brody, 1986); d) changes in marital and fertility patterns (Abel, 1987); and continued growth of women's labor force participation. A greater understanding of factors that affect changes in the care network may suggest policy incentives, such as family leaves in the workplace, or service options that will facilitate continuity of informal community care. The utility of such policy options depend on the assumptions first, that caregiver burden may be minimized by provision of a wide range of community services, thus preventing premature institutionalization, and, second, that family members are likely to supplement their care with selective use of community services, rather than use formal community services as a substitute for direct provision of care.

Research thus far points to changes in the older person's level of disability or such changes in the caregiver's situation as widowhood or feelings of burden as the primary predictors of network changes (Birkel and Jones, 1989; Johnson and Catalano, 1983; Stoller and Earl, 1983; Stoller and Pugliesi, 1988). For example, Stoller and Pugliesi (1988) found that over a seven year time period in a non-metropolitan sample of elderly, the size of the helper network expanded in response to declines in health status and, generally, this expansion represented informal sources that were increasingly distant in relationship from the older person.

This chapter examines the relative impact of caregiver burden and elder frailty on the stability of the informal instrumental care network of frail older persons over a two year period. Emotional and instrumental support are both needed to sustain an individual in the community. Emotional support, however, can rarely be purchased and is typically not included in the policy domain; thus, this chapter refers to instrumental support only. Two research questions are addressed: 1) How stable are informal instrumental support networks over a two-year period? 2) To what extent, does the burden/strain of the primary caregiver affect changes in the structure of care networks, controlling for level of impairment? Following a description of stability and change in the size and intensity of help of informal, we propose and analyze a model of the effect of primary caregiver burden on changes in the informal network structure. Although stability is implicitly interpreted as a desirable feature of the caregiving network, changes in the source and number of members of the caregiving network may at times have a salutary influence on continuing community care.

Sample and Measures.

Our study sample for this chapter focuses on those older persons who received care from immediate family members. The caregiver and elder survey data were linked through an elder identification number; there was no comparable identification check for caregiver and helpers described within the 1982 and 1984 elder data. Furthermore, we could not match specific helpers in 1982 with specific helpers in 1984. A noted in Chapter 2, an analysis of the probable match between the subsample of caregivers and helpers identified by the older person suggested that all of the spouses in the caregiver sample matched spouse information in the elder survey; for adult child primary caregivers, some discrepancy in exact match of identifying characteristics, e.g. living arrangements, was observed in 25 cases. These cases were retained in the analysis, however, resulting in a longitudinal base sample of 644 persons who remained in the study between 1982 and 1984. Twenty--nine cases had missing data on key helper variables and were dropped from the longitudinal analyses.

Our analysis of caregiver networks examine structural rather than interactional components. We examined three structural dimensions of informal. instrumental task support: availability of helpers indicated by the number of people in the elder's household; , number of informal helpers identified by the older person who assist with at least one ADL and/or IADL activity; and extensiveness of informal help measured by total days of help provided by all the informal helpers of a specific elder. The characteristics of the caregiver included in this chapter are relationship to older person, sex, health status and personal and interpersonal burden. Characteristics of the older person are level of functional ability, gender, age, prior hospitalization and number of chronic conditions. An indirect measure of severe cognitive functioning, the presence of a proxy respondent on the cognitive status items, provides a crude indicator of the existence of cognitive or severe disabling functional limitations.

Plan of Analysis

The effect of caregiver burden on network stability and change is determined in part by the amount of change that occurs. We interpret the size and extensiveness of the informal helper networks in 1982 as the primary source of the size and extensiveness of the respective helper networks in 1984 (Kessler and Greenberg, 1982). This interpretation recognizes the heterogeneity of caregiver situations at Time 1, leaving the process of initial formation of the helper network unexplained.

We first assessed the amount and direction of change in the structure of informal helper networks, i.e. the composition of the helper network, the number of informal helpers, and the number of person days of help received. We then investigated the extent to which network changes are associated at the bi-variate level with selected demographic and health characteristics of the primary caregiver and the older frail person.

To study the effect of caregiver burden on changes in the dimensions of the informal care network, we developed a latent variable structural model of relationships between caregiver burden, changes in functional level, and changes in informal network structure. Linear structural models (Joreskorg and Sorborn, 1986) were selected for this analysis of change because of their ability to account for measurement error in longitudinal models, and multiple indicators of health status and task support networks. Furthermore, this approach permits assessment of the significance of individual parameters, and an integrated system of relationships. In addition to the basic model, we examined whether the model parameters describe spouse and adult child caregivers in the same way.

Results

Description of Change in Informal Helper Networks

Helper networks are composed primarily of intimate family members providing help alone. Approximately 41 percent of the helpers in 1982 were spouses only and about one-quarter were adult-children only. Table 4-1 presents the distribution of 1982 helper network composition by network composition, institutionalization and mortality in 1984. Mortality rates were relatively consistent across all types of helper networks, ranging from 27 percent in spouse and adult child networks to 22 percent in spouse and other networks. Those with spouse only networks had the lowest institutionalization rates (4.1 percent), and those with adult child only networks had the highest (10.8 percent). Shifts in network composition tended to remain within network groupings defined by the primary caregiver relationship. For example, changes in spouse only networks were in the direction of including adult children and others in a spouse plus network, rather than shifting to a non-spouse defined network. A similar pattern occurred among networks composed of adult children caregivers. Overall, the networks dominated by the single relationship of a primary caregiver remained the most stable.

The distribution of informal network characteristics in 1982 and 1984 for those older persons who remained in the community is presented in Table 4-2. Average household size did not change over the interval, with approximately 2.4 members in each period. It is important to note that less than 10 percent of the older persons lived alone, and the majority lived in two-person households.

There was little change in the mean number of informal helpers, 1.69 in 1982 and 1.77 in 1984. Examination of patterns of individual change showed that approximately one-half had only one helper in both years, and 4 percent did not receive any help in 1984.

The average number of person days of help was similar in 1982 and 1 approximately 8 days. The proportion not receiving any days of care in 1984 doubled, but overall remained small (7.5 percent).

Further examination of patterns of change in these dimensions were conducted to assess if observed variations were due to sampling error, unreliability of measurement, or a uniform shift of all scores with no individual differences in relative position. Table 4-3 describes the change patterns on a variety of dimensions: the percent with change in each direction, a paired t-test which measures if mean change within individuals differs from that expected by chance, the stability coefficient indicated by the Pearson product moment correlation, and the Q^2 statistic which partitions individual and structural levels of change.

The distribution of change scores indicates general stability in the living arrangements of frail older persons, but variation in individual shifts among the number of informal helpers and the number of person days of help. Household size remained the same in over 80 percent of the cases. But the number of helpers and extensiveness of help increased or decreased in almost equal proportions. Change was greatest in the extensiveness of help; notably, one third of the frail elders received less helper days in 1984 than in 1982. The paired t-test for correlated samples of all of the network dimensions was non significant, suggesting that the overall individual changes did not differ from sampling error.

The correlation coefficient between time 1 and time 2 measures provides a summary measure of stability. These correlations are moderate and similar for the number of helpers (.345) and number of person days (.313), but high for household size (.717). Thus, much of the variance in helper size and person days in 1984 is not explained by network size and level of help in 1982.

The concept of change has two aspects: the relative contribution between individual changes (shifts in relative position), and changes in the overall distribution (uniform movement of all scores). In other words, group-level measures of change, such as mean differences, may not reveal the extent to which individual-level change has occurred or the group as a whole has shifted. Increases and decreases in size of network may cancel each other out when looking at the group as a whole. The Q^2 statistic (Kessler and Greenberg, 1982) represents the mean sum of squares of differences that can be partitioned to the amount of individual change (the first term in Q^2) relative to the amount of structural group change (the second term). For example, if there was a general trend for all elders to use more informal helpers in 1984 than in 1982, the second term would be larger than the first. The total Q^2 statistic for household size and number of informal helpers is quite small, confirming that relatively little change occurred over the two year period (Table 4.3). A greater, but still modest, amount of change occurred in the number of person days of help, largely the result of individual shifts in levels of help that in effect cancel each other out in terms of aggregate change.

Characteristics of the Primary Caregiver, the Older Person, and Network Change

We next address whether mean differences in informal level of help provided and change over the two year period vary by specific characteristics of the primary caregiver and the older person. Identification of these characteristics can provide markers for groups with changing service needs.

Table 4-4 presents the mean levels (and standard deviation) of each network dimension in 1982 and the mean direction of change in level in 1984 by selected characteristics of the primary caregiver. Oneway analysis of variance tested the statistical significance of mean differences between groups within each attribute. In 1982, older persons cared for by spouses tended to have smaller households, fewer other informal helpers, and receive about 20 percent less person days of help than those cared for by adult children. These findings are similar to others in the literature (Horowitz, 1985), that show that spouses are more likely to provide care with fewer supplementary helpers. These findings also suggest that spouses provide slightly less extensive aid than adult children, although the results may be confounded by the extent to which older spouses fail to consider some certain IADL activities such as preparing meals to be special help. Networks with spouse caregivers had a significant increase in the number of informal helpers significantly in 1984, but no corresponding change in extensiveness of help.

Although there was little difference in number of helpers between male and female caregivers, networks defined by male caregivers increased number of helpers in 1984. Younger caregivers had more helpers and more person days in the informal care network, possibly because younger caregivers may be participating in multi-generational families. There were no significant differences in number of household members, number of informal helpers or informal person days by education or either type of burden. Networks of those with high personal burden provided significantly more person/days of help than those with low personal burden (8.7 versus 7.9), but with little difference in number of helpers. In sum, most caregiver attributes showed relatively little association with change in the size of the informal care network. Care networks of younger caregivers and those with high personal burden, however, tended to have more days of informal help.

Age, marital status, education and race of frail older persons were associated with informal network attributes (Table 4-5). Persons who are older and non-white with lower education levels tend to have larger households, more informal helpers, and larger amounts of help. Married persons have smaller households, fewer helpers, and lower levels of days of help. Significant changes in network structures over the two-year interval were associated with the older person's gender, and marital status. Frail men and married persons had significantly more helpers and received more help in 1984 than frail women. The size of these change differences were small, however. Since older men are more likely to be married than older women, these results probably represent the same underlying phenomena.

Changes in health status of the frail older person over the two years were associated with changes in number of informal helpers and levels of informal help (Table 4-5). Those who decline in number of ADL and IADL limitations (i.e. improve in functional status) have a smaller average number of informal helpers. Similarly, the number of days of help decreases when ADL and IADL functional status improves. The number of informal helpers shifts less dramatically as functional disability increases, i.e. differences between those with no change in functional status and those who increase disability are modest. This result may be because of the number of those with high levels of disability within the no change group. Informal helpers appear to drop out of the helper network when the need is no longer there, and in situations of increasing need, increase their level of effort.

In examining Table 4-4 and Table 4-5 together. we are struck by the contrast between the size of the mean changes and the standard deviations of the changes, particularly in number of helpers and days of help. This suggests the earlier analysis of change scores, in which many respondents are both adding and relieving helpers.

Table 4-6 examines the contemporaneous association between the 1984 level of informal help and health characteristics and confirms the need-response pattern of changes in level of help across a broad array of health measures. Larger households occurred in instances of higher IADL disabilities or cognitive disturbance, but not other indicators of health status. Thus, it is difficult to identify any general patterns that may link health status and household size. The size of the informal helper network differed by functional and cognitive levels, but not by recent hospitalization or chronic conditions. Those with higher levels of ADL and IADL disability received significantly more days of help. Thus it appears likely that those older persons most in need of assistance with functional limitations receive the highest levels of assistance from their informal network of helpers and draw on a larger pool of helpers. Hospitalization is not associated with received level of informal help. Hospitalization could occur any time in the previous 12 months, and since most hospitalizations occurred prior to the week referenced by the help question, we would not expect any direct effect on current level of help. Those with more chronic conditions receive more days of help, but without any corresponding increase in informal network size.

In sum, these descriptive results show that although a modicum of change occurs among individuals in the number of informal helpers in the older person's network and in the level of help received, overall the helper networks remained fairly stable for those individuals who remain in the community. Not unexpectedly, changes in household size occur infrequently. Changes in network size and intensity of help appear to correspond with changes in the functional abilities and health status of the frail older person. Neither dimension of caregiver burden was associated with change in the size of the informal helper network at the bivariate level, although those older persons cared for by caregivers with high personal burden were likely to receive more help in 1982 and in 1984. The generally large standard deviations associated with the change scores remind us of the wide range of variability underlying these general trends.

The Role of Caregiver Burden in Informal Network Change

The descriptive and bivariate results do not adequately address the role caregiver burden may play in a multi-variate model of change in informal task support networks. Although helper networks may function well in meeting short-term need, long-term provision of support that results from continuing or increasing disability may place demands on a network that are beyond its capacity. The dominance of the primary caregiver suggests that the burden, strain, and/or distress of the primary caregiver can affect many care outcomes, notably service use, caregiver mental health, family relationships, risk of institutionalization, (Horowitz, 1985). We hypothesize that, controlling for changes in level of disability, caregiver burden will affect changes in the informal task support network. Specifically, we proposed that caregiver burden will be positively associated with an increase in the task support network of a frail older person over a two year period.

To test this hypothesis, we developed a conceptual and measurement model of change to examine the effect of each dimension of burden, controlling for change in functional disability. This model is presented in Figure 4-1.

The hypothesis of increases in network task support in response to higher levels of caregiver burden presupposes a model of positive family support relationships in which family members respond to the needs of one another, and helpers removed in distance from the immediate family become involved only when needed (Stoller and Pugliesi, 1989). Secondary informal caregivers are most likely to be other family members (Tennestedt, McKinlay, and Sullivan, 1989). Because these helper networks represent a core of close relationships, members with long-standing ties are not easily replaced by other sources of help, but may contribute additional assistance when needed or asked. The psychosocial stress model of House et al, (1988) and others suggests that social supports modify health and stress outcomes, but the form this support takes over time is rarely studied. Our model argues that informal helpers will increase task support in response to both caregiver burden and changes in the older person's level of frailty. Specificity models of social support propose that different kinds of support have different outcomes. We anticipated that personal burden will be a stronger determinant of change than interpersonal burden because task support is a more specific response to the time and activity constraints represented by personal burden. Interpersonal burden, on the other hand, would be more likely influenced by emotional support or other forms of coping not measured in this study.

The time span within which changes occur within a caregiving situation may be highly individualistic. There have been insufficient studies to predict appropriate time lags for change processes. Clinical data suggest that the decision to institutionalize is frequently made in a crisis, and changes in the care network may occur in a similar fashion. We would anticipate, however, that changes in number of helpers would not occur instantaneously in response to difficulties experienced by the primary caregiver, but rather take some time to evolve. Thus, we anticipate that reactions to caregiver burden at Time 1 will become evident at Time 2, a lagged effect. This assumption presupposes that Time 1 measures occurred within a stable caregiving period, rather than one in the midst of change.

This model of caregiver burden and change in network task support may be conditioned by socio-demographic factors that potentially interact with caregiver burden. Although our previous research found that the process of caregiver burden did not differ by relationship of caregiver to the frail older person (Miller, McFall, and Montgomery, 1988), the longer-term effects may vary if the primary caregiver is a spouse or adult child. We anticipate that changes within the helper networks of spouse caregivers will be less responsive to the effects of caregiver burden than those of adult children. In general, spouses are less likely to have help from other caregivers and are most persistent in their commitment to caregiving (Horowitz, 1985). Adult children potentially have larger family structures to call on, and may be less willing to sustain high levels of care for a long period of time.[1]

We estimated the proposed model using the structural equation approach of LISREL (Joreskog and Sorbom, 1986). This approach explicitly incorporates a measurement model into the estimation process, enabling specification of error not only within the measurement of concepts, but also in repeated measures over time.

First, we assessed the measurement of task support network. This construct was indicated by three items: household size, number of informal helpers and number of person days of help, at each of two time points. The model assumed autocorrelated measurement error variances for each network indicator and equivalent parameters of

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[1] We also considered a second factor that may operate independently of relationship of the caregiver, the level of disability of the older care recipient. Caregivers with high levels of burden providing care to older persons with high levels of functional disability may be in greater need of additional help from other members of the older person's informal network than those with lower levels of burden and less impaired care recipients. However, preliminary analyses showed no support for this idea, as the interaction between personal burden and level of ADL disability had no effect in multiple regression equations of change in helper network attributes.

the measurement model for the two time periods. The fit of the model was quite good, with the likelihood ratio chi-square 3.89, 5 degrees of freedom, probability = .56.

The measurement of personal and interpersonal burden was derived from previous work (Miller, McFall, and Montgomery, 1988). The six indicators of personal burden and four indicators of interpersonal burden were assessed in a confirmatory factor analysis using maximum likelihood estimation. The model includes a number of correlated measurement error as shown in Figure 4-2. The fit of the model is good, with a relative likelihood chi-square of 69.28 with 31 degrees of freedom. Two other measures of fit, the goodness of fit index and the adjusted goodness of fit index (Joreskog and Sorborn, 1984) were .98 and .97, respectively. Table 4-7 presents the factor loadings and indicates significant loadings on all indicators for the two constructs. The two burden constructs were strongly correlated with one another (r = .72).

The full LISREL model is presented in Figure 4-2. In general, the model states that task support network in time 2 is a function of the network at time 1, functional limitations at time 2, and interpersonal and personal burden. Functional limitations in 1984 are hypothesized to be a function of limitations in 1982. The model as shown in Figure 4-2 incorporates a number of relevant features. First, the measurement of task network support at time 2 was constrained to be equal to that in time 1, a position that was supported in analyses reported above. In addition, we correlated measurement errors for items across time 1 and time 2 for task support and functional limitations, thus taking into account the likelihood of autocorrelated measurement error. The fit of the model is judged satisfactory based on a number of criteria. The relative likelihood ratio chi-square was 252.32, with 146 degrees of freedom. The goodness of fit index was .96, with adjusted goodness of fit index of .94. Examination of residuals suggested that the residuals did not violate the multi-normal distribution assumption.

Table 4-8 presents the unstandardized regression coefficients for the change in informal task support network and the correlation matrix of constructs in the model. We see that the effects of personal and interpersonal burden on change in the task support network are insignificant. Rather, the size of the task support network in 1984 is primarily a result of size in 1982 and the contemporaneous effect of functional limitations. As in our previous work (Miller, McFall, and Montgomery, 1988), personal and interpersonal burden are greater in those with more functional limitations. Functional limitations in 1982 are also positively related to the task support network in 1982 and to functional limitations in 1984. The model explains 58 percent of the variance in 1984 task support network. From the correlation matrix, we see that personal and interpersonal burden are strongly correlated (.69) and more strongly associated with functional limitations than with network structure at either time period.

We also assessed the possibility that the effects of caregiver burden might vary by relationship of caregiver. Adult children have more potential helpers to draw on and more competing responsibilities, and therefore, may have greater shifts in the number of helpers and levels of help than spouses. As a first step towards examination of the similarity of structural paths in separate group analyses of spouse and adult child caregivers, we tested the equivalence of the measurement structure between the two groups. If the factor loadings associated with the indicators of task support networks, caregiver burden, or functional limitations are not the same in the two groups over time, additional comparisons of the structural paths will be meaningless. Our earlier analysis (Miller, McFall, and Montgomery, 1988) showed that the factorial structure of caregiver burden was equivalent for spouse and adult child caregivers. Thus the focus of interest here is the equivalence of the task support network and functional limitations measures between the two groups.

Group comparisons are based on successive comparisons of the fit of models in the two groups. As a first step in comparing networks of those with spouse and adult child caregivers, we tested the equivalence of the measurement structure in the two groups. If factor loadings associated with the major constructs, functional limitations, burden and task support network, are not similar, additional comparisons of the structural relationships are meaningless. Our earlier analyses (Miller, McFall, and Montgomery, 1988) suggested that the measures of functional limitations and burden were equivalent for spouses and adult children. Essentially, we are extending this comparison to include the measurement of task support network.

We compared the fit of the model which did not impose equivalence constraints (Chi-square = 392.31, 292 df) with the model imposing equivalent factor loadings (chi-square 422.41, 303 df). A test of the difference in the chi-square values for the two nested models (Chi-square difference 30.1, 11 df, probability < .01) showed that introduction of the constraint in measurement results in a significant worsening in fit. That is, the measurement structure for the two groups differ. Examination of the lambda estimates for each group separately suggested that the unstandardized factor loadings on task support network differed between spouse caregivers and adult child caregivers in the contribution of number of informal helpers (3.826 for spouses and .448 for adult children) and the number of days of help (27.02 for spouses, 5.699 for adult children). The factor loadings for the components of either measure of caregiver burden, or functional limitations did not differ between the two groups. Although, we cannot test more specifically if the effect of caregiver burden differs between adult child and spouse caregivers, examination of the model applied separately to spouse and adult child caregivers confirmed that neither dimension of caregiver burden had a significant effect on change in helper networks for either relationship group.

Conclusion

This chapter analyzed the amount of change in informal helper networks between 1982 and 1984, and influence of two dimensions of caregiver burden on that change. We found that many frail older persons received help from more than one primary caregiver, even with the sample restriction to sole primary family caregivers in 1982. In 1982, slightly under one-half of the sample identified more than one informal helper and this percent increased to over one-half in 1984.

The first research question focused on the degree of stability and change in the informal task support network over a two year period. The results showed that informal task support networks had more stability than change in composition and size, with a slightly higher amount of change in extensiveness of help provided. Specifically, household size was most stable, followed by some fluctuation in the number of informal helpers, and even more fluctuation in the number of informal persons days of help. The sociodemographic characteristics of the caregiver and frail older person were associated with change per se in highly selective ways. Personal burden of the caregiver was associated with an increase in days of informal and formal help. Increased functional disability during the two year period, and poorer health status of the frail older person in 1984, represented by ADL and IADL disability and cognitive problems were related to larger size networks and higher levels of care in informal helper networks.

The second research question addressed the specific effects of personal and interpersonal burden on changes in the helper network, controlling for changes in functional status. Based on structural equation estimations, neither personal nor interpersonal burden had any influence on changes in informal network task support. This pattern did not change when differences between older persons cared for by spouse and adult child primary caregivers were evaluated. The minimal amount of change in the informal task support network of older persons that occurred was primarily determined by changes in functional status of the older person.

Within the context of the measures available in this study, these results clearly demonstrate that the caregiver burden did not influence change in the informal task support network. In addition to providing more verification of the overall stability of the informal caregiver network of frail older persons, the assumption that family and other informal caregivers respond to the needs of the frail older person continues to be supported. For family caregivers, need appears to be defined by changes in the ftinctional and health status of the frail older person, rather than the primary caregiver's responses to care. Family members with strong ties contribute additional assistance when needed. Unfortunately, since we do not have contemporaneous measures of burden in 1984, we cannot assess if the provision of this additional help is accompanied by increases in felt burden.

The amount of overall stability in informal care networks suggests at least two general implications for policy. First, concerns about the "woodwork effect" are misplaced, as family members demonstrate commitment to provide care when needed. This ability to respond to the older person's needs, however should not necessarily be construed to indicate that no additional programmatic or service support is needed, since these results do not encompass information about the opportunities foregone, or other types of emotional or health strains experienced within the stable helping network. Second, policies to relieve caregivers cannot be considered in isolation from attention to the health care needs of frail older persons who exhibit functional limitations. As our multivariate analysis showed, changes in level of disability have extensive effects on the family and helper system.

FIGURE 4-1. Model of Caregiver Burden and Changes in Network Structure

***NOTE**: Although this figure was referenced within the report, it was not included in the final version of the report. If it is discovered in an earlier version, it will be added.*

FIGURE 4-2. Measurement Model of Caregiver Burden and Changes in Network Structure

***NOTE**: Although this figure was referenced within the report, it was not included in the final version of the report. If it is discovered in an earlier version, it will be added.*

TABLE 4-1. Composition of Informal Helper Networks: Percentage of 1982 Helpers by 1984 Helper.

1984 Composition	1982 Composition				
	Spouse Only n=386	Spouse/ Adult Child n=113	Spouse/ Other[a] n=64	Adult Child Only n=260	Adult Child/ Other[a] n=110
Spouse only	45.3	14.2	23.4	0.0	0.0
Spouse/ Adult Child	13.2	29.2	12.5	0.4	0.9
Spouse/Other	5.2	2.7	20.3	0.0	0.0
Adult child only	1.3	7.1	0.0	44.2	26.4
Adult child/ Other	.3	1.8	0.0	15.0	37.3
Other[a]	.5	1.8	6.3	0.0	2.7
No helpers	5.7	7.1	7.8	5.4	2.7
Nursing home	4.1	8.8	7.8	10.8	7.3
Died	24.4	27.4	21.9	24.2	22.7
Total Percent	100.0	100.0	100.0	100.0	100.0

a. Other includes other relatives, friends, neighbors.

TABLE 4-2. Distribution of Informal Network Characteristics 1982-1984 (n=615)				
	1982		1984	
	n	%	n	%
A. NUMBER OF HOUSEHOLD MEMBERS				
One	51	8.3	58	9.4
Two	392	63.7	393	63.9
Three	104	16.9	103	16.7
Four - seven	68	11.1	61	11.0
Mean	2.39		2.35	
S.D.	1.03		1.02	
B. NUMBER OF INFORMAL HELPERS				
None			25	4.1
One	364	58.2	304	49.4
Two	135	22.0	157	25.5
Three	76	12.4	75	12.2
Four - eight	40	6.6	54	8.9
Mean	1.69		1.77	
S.D.	1.03		1.16	
C. NUMBER OF PERSON DAYS				
None	17	2.8[a]	46	7.5
One - six	49	8.0	59	9.6
Seven	367	59.7	310	50.4
Eight-twelve	95	15.4	105	17.1
Thirteen-forty two	87	14.1	95	15.4
Mean	8.33		8.07	
S.D.	4.51		5.01	

a. This category represents those who were identified as helpers by the frail elders but who did not provide any specific help in the previous two weeks.

TABLE 4-3. Changes in Number/Type of Informal Network Structure, 1982-84				
	Household Members		**Informal Helpers**	
	n	**%**	**n**	**%**
A. NUMBER IN HOUSEHOLD AND NUMBER OF INFORMAL HELPERS				
DECREASE				
-2 TO -5[1]	19	3.3	47	7.6
-1	48	7.8	97	15.8
NO CHANGE				
0	498	81.0	311	50.6
INCREASE				
1	31	5.0	100	16.3
2 to 5	18	2.9	60	9.8
MEAN (sd)	-.041 (.772)		.075 (1.26)	
PAIRED t-TEST				
t-value (df=615)	1.31, p=.192		-1.46, p=.141	
STABILITY COEFFICIENT				
Pearson's r	.717		.345	
Q^2 PARTITIONED	.59 + .0017		1.59 + .0064	
	Person Days			
	n		**%**	
B. NUMBER OF PERSON DAYS				
DECREASE				
-8 to -35	30		4.9	
-4 to -7	86		14.0	
-1 to -3	63		10.2	
NO CHANGE				
0	270		43.9	
INCREASE				
1 to 3	77		12.5	
4 to 7	55		8.9	
8 to 27	34		5.6	
MEAN (sd)	255 (5.578)			
PAIRED t-TEST				
t-value (df =615)	1.13, P=.257			
STABILITY COEFFICIENT				
Pearson's r	.317			
Q^2 PARTITIONED	31.11 + .068			
1. The lowest number for household members is -4; for informal helpers the lowest number is -5				

TABLE 4-4. Mean (Standard Deviation) Level of Informal Help in 1982 and Amount of Change by 1982 Characteristics of the Primary Caregiver (n=614).

Caregiver Characteristics	Household Members		Informal Helpers		Person Days		n
	1982	Change84	1982	Change84	1982	Change84	
RELATIONSHIP							
Spouse	2.2* (.58)	-.03 (.61)	1.4* (.85)	.16* (1.38)	7.5 (2.8)	-.04 (5.9)	373
Adult child	2.7 (1.4)	-.06 (.97)	2.1 (1.1)	-.06 (1.4)	9.65 (6.1)	-.58 (6.8)	242
SEX							
Male	2.3* (.86)	-0.4 (.7)	1.7 (.9)	.24 * (1.2)	8.1 (4.7)	.26 (5.5)	204
Female	2.4 (1.1)	-.04 (.8)	1.7 (1.1)	-0.3 (1.3)	8.5 (4.7)	-.25 (5.6)	411
AGE							
14-55	2.8 (1.6)	-.03 (.7)	2.3* (1.2)	-.17 (1.4)	9.9* (6.6)	-.92 (7.6)	135
56-64	2.5 (1.0)	-.07 (.7)	1.8 (1.1)	.07 (1.2)	8.6 (4.8)	-.25 (5.0)	141
65-74	2.2 (.5)	.00 (.5)	1.5 (.9)	.21 (1.2)	7.6 (2.7)	-.49 (4.7)	223
75 and over	2.2 (.)	-.09 (.8)	1.5 (.8)	.09 (1.1)	7.6 (3.3)	.26 (4.9)	116
EDUCATION							
< high school	2.3 (.9)	-.03 (.7)	1.6 (.9)	.16 (1.2)	8.1 (3.7)	.12 (5.3)	340
High school	2.5 (1.2)	-.04 (.9)	1.7 (1.1)	.01 (1.3)	8.4 (5.3)	-.51 (6.3)	158
> High school	2.4 (1.1)	-.09 (.8)	1.8 (1.1)	-.07 (1.1)	8.9 (5.4)	-.88 (5.1)	115
PERSONAL BURDEN							
Low	2.4 (1.0)	-.02 (.8)	1.7 (1.0)	.02 (1.2)	7.9* (4.2)	-.28 (5.1)	3.04
High	2.4 (1.0)	0.06 (.8)	1.7 (1.0)	(.12) (1.3)	8.7 (4.5)	-.23 (6.0)	311
INTERPERSONAL BURDEN							
Low	2.3 (.9)	-.05 (.7)	1.7 (1.0)	.01 (1.0)	8.1 (4.3)	-.36 (5.4)	381
High	2.5 (1.1)	-.02 (.9)	1.7 (1.0)	.18 (1.2)	8.7 (4.8)	-.08 (5.8)	234

* Probability < .05

TABLE 4-5. Mean (Standard Deviation) Level of Informal Help in 1982 and Amount of Change by Characteristics of the Frail Older Person (n=614).

	Household Members		Informal Helpers		Person Days		n
	1982	Change84	1982	Change84	1982	Change84	
SEX							
Male	2.3 (.83)	-.02 (.51)	1.5 (.91)	.24 * (1.2)	7.7 (3.1)	.11 (4.6)	245
Female	2.4 (1.1)	-.06 (.91)	1.8 (1.1)	-.03 (1.3)	8.8 (5.2)	-.49 (6.1)	370
AGE							
65-69	2.3* (.82)	-.01 (.79)	1.4* (.89)	.13 (1.2)	7.5* (4.1)	.01 (5.2)	132
70-74	2.3 (.93)	-.01 (.68)	1.6 (.98)	-.01 (1.2)	7.8 (4.0)	-.46 (5.3)	155
75-79	2.3 (.88)	-.02 (.75)	1.7 (1.0)	.21 (1.3)	8.1 (4.1)	.05 (5.8)	116
80 plus	2.6 (1.2)	-.08 (.83)	2.0 (1.1)	.03 (1.3)	9.3 (5.1)	.44 (5.8)	212
EDUCATION							
< High school	2.5* (1.1)	-.04 (.93)	1.8 (1.0)	.13 (1.4)	8.6 (4.4)	-.07(5.9)	324
High school	2.2 (.87)	.01 (.50)	1.6 (1.0)	.01 (1.2)	7.7 (4.4)	.29 (5.2)	207
> High school	2.3 (.81)	-.07 (.52)	1.5 (.95)	-.01 (1.1)	8.0 (5.0)	-.74 (4.7)	70
RACE							
Nonwhite	2.7* (1.4)	.04 (.88)	1.9* (1.2)	.17 (1.5)	9.6* (5.9)	1.04* (7.5)	81
White	2.3 (.95)	-.05 (.75)	1.7 (1.0)	.06(1.2)	8.2 (4.4)	-.45 (5.2)	534
1982 MARITAL STATUS							
Not married	2.6* (1.4)	-.02 (.95)	2.1* (1.2)	-.06* (1.3)	9.5* (5.9)	-.48 (6.8)	221
Married	2.3 (.68)	-.05 (.65)	1.5 (.87)	.15 (1.2)	7.6 (3.2)	.12 (4.8)	392
CHANGE IN ADL LEVEL							
Decline	a	-.07 (.8)	a	-.15* (1.2)	a	-1.7* (5.4)	216
No change		-.04 (.7)		.18 (1.3)		.25 (5.2)	203
Increase		-.0 (.66)		.21 (1.3)		.80 (5.8)	196
CHANGE IN IADL LEVEL							
Decline	a	-.09 (.77)	a	-.08* (1.3)	a	-1.4* (5.8)	225
No change		-.04 (.65)		.15 (1.2)		.05 (5.8)	147
Increase		.01 (.83)		.18 (1.2)		.65 (5.0)	243

a. Not applicable

* =Probability <.05

TABLE 4-6. Mean Level of Informal Help in 1984 by Health Characteristics of the Frail Older Person in 1984. (n=614).

Older Person Characteristics	Household Members		Informal Helpers		Person Days		N
	Mean	St. Dev.	Mean	St. Dev.	Mean	St. Dev.	
ADL LIMITATIONS							
Low	2.27	.90	1.62	1.13*	5.99	4.60*	137
Moderate	2.36	1.11	1.75	1.08	7.51	4.22	200
High	2.43	1.1	1.95	1.23	9.50	5.28	278
IADL LIMITATIONS							
Low	2.16	.74*	1.30	1.00*	5.39	4.29*	172
Moderate	2.38	1.1	1.94	1.14	8.72	4.57	234
High	2.46	1.1	1.96	1.20	9.55	5.17	209
1984 PROXY FOR COGNITIVE EXAM							
No	2.18	.82*	1.68	1.16*	7.35	4.82*	358
Yes	2.59	1.19	1.89	1.14	9.17	5.03	253
HOSPITALIZED PREVIOUS YEAR							
No	2.35	.96	1.68	1.0	7.98	5.31	376
Yes	2.44	1.12	1.70	1.1	8.33	4.37	230
CHRONIC CONDITIONS							
0 - 2	2.29	.97	1.65	1.09*	7.41	4.7*	308
3 - 7	2.41	1.06	1.88	1.22	8.73	5.22	307

* Probability F-value <.05

<table>
<tr><th colspan="3">TABLE 4-7. Measurement Model of Caregiver Burden</th></tr>
<tr><th>Construct and Item</th><th>Lambda</th><th>T-Value</th></tr>
<tr><td colspan="3">PERSONAL BURDEN</td></tr>
<tr><td>Limits on social life</td><td>1.00[a]</td><td>0.00[a]</td></tr>
<tr><td>Constant attention</td><td>1.03</td><td>13.50</td></tr>
<tr><td>Worsening health</td><td>.81</td><td>12.29</td></tr>
<tr><td>Cost more than afford</td><td>.67</td><td>10.55</td></tr>
<tr><td>Care when not well</td><td>1.14</td><td>12.58</td></tr>
<tr><td>Emotional strain</td><td>1.25</td><td>13.44</td></tr>
<tr><td colspan="3">INTERPERSONAL BURDEN</td></tr>
<tr><td>Forgetting things</td><td>1.00[a]</td><td>0.00[a]</td></tr>
<tr><td>Embarrassing behavior</td><td>.82</td><td>13.04</td></tr>
<tr><td>Senile lapses</td><td>.93</td><td>13.55</td></tr>
<tr><td>Yelling and upset</td><td>.84</td><td>11.70</td></tr>
<tr><td colspan="3">a. Fixed parameter</td></tr>
</table>

<table>
<tr><th colspan="7">TABLE 4-8. Unstandardized Structural Parameters and Correlation Matrix of LISREL Network Model</th></tr>
<tr><th rowspan="2"></th><th colspan="6">1984 Task Support Network</th></tr>
<tr><th colspan="3">Unstandardized Coefficient</th><th colspan="3">Standard Error</th></tr>
<tr><td colspan="7">A. STRUCTURAL PARAMETER ESTIMATES</td></tr>
<tr><td>Task support network, 82</td><td colspan="3">.630</td><td colspan="3">.071[a]</td></tr>
<tr><td>Functional limitations, 84</td><td colspan="3">.128</td><td colspan="3">.024[a]</td></tr>
<tr><td>Personal burden, 82</td><td colspan="3">-.175</td><td colspan="3">.112</td></tr>
<tr><td>Interpersonal burden, 82</td><td colspan="3">.014</td><td colspan="3">.113</td></tr>
<tr><td colspan="7">a. T-value greater than 1.96, P < .05 level</td></tr>
<tr><th></th><th>1</th><th>2</th><th>3</th><th>4</th><th>5</th><th>6</th></tr>
<tr><td colspan="7">B. CORRELATION MATRIX OF LATENT VARIABLES IN NETWORK MODEL</td></tr>
<tr><td>1. Task support network, 82</td><td>1.0</td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>2. Functional limitations, 82</td><td>.367</td><td>1.0</td><td></td><td></td><td></td><td></td></tr>
<tr><td>3. Personal burden, 82</td><td>.205</td><td>.557</td><td>1.0</td><td></td><td></td><td></td></tr>
<tr><td>4. Interpersonal burden, 82</td><td>.136</td><td>.371</td><td>.696</td><td>1.0</td><td></td><td></td></tr>
<tr><td>5. Functional limitations, 84</td><td>.282</td><td>.768</td><td>.427</td><td>.285</td><td>1.0</td><td></td></tr>
<tr><td>6. Task support network, 84</td><td>.687</td><td>.435</td><td>.155</td><td>.105</td><td>.485</td><td>1.0</td></tr>
</table>

V. THE EFFECT OF CAREGIVER BURDEN ON STABILITY AND CHANGE IN THE FORMAL TASK SUPPORT NETWORK OF FRAIL OLDER PERSONS

The use of assistance from organizations such as home health care agencies and paid helpers is one area of intersection between informal care and the formal care system. Although use of a paid helper may be an informal act because control is maintained by the older person or the caregiver rather than an agency, this source of help is governed by contractual rather than affiliative norms. Formal help is typically provided or requested for assistance with such concrete activities as household maintenance, rather than emotional support for the frail person. In fact, Litwak (1985) argues that the formal service system is best suited for providing routinized and specialized task activities, whereas the family system can best handle nonuniform, unpredictable, and nontechnical tasks. This view of the functional complementarity between the formal and informal sector is somewhat artificial, as family members often perform tasks in the context of emotional support, and formal services are most acceptable when delivered in a personalized fashion. Nevertheless, Litwak's distinction appears to reflect patterns of service delivery in which emotional support can rarely be purchased and is not considered part of the policy domain.

Many studies of the use of formal helpers by the elderly have applied Anderson's model of predisposing, enabling, and need factors as individual-level determinents of formal service use (Anderson and Newman, 1973). Predisposing variables are those which exist prior to illness/frailty onset or the time period in question, representing demographic, social structural and attitudinal-belief variables that are associated with an increased propensity to use services. From a policy perspective, while predisposing variables are not amenable to manipulation, they represent opportunities to target special service needs. Enabling variables emphasize the resources which promote or inhibit use of formal help. Policy options may be created that may increase resources of a targeted group, e.g. income supplements, if the goal is to promote use of formal services or promote equity. The efficacy of enabling factors may also reflect the attributes of the service delivery system. Need factors, i.e. level of illness or impairment, are considered the proximate cause of formal service use. Policy efforts may be directed to insuring that a continuum of services meeting a range of needs are available.

Most of this research has been cross-sectional rather than longitudinal in design. Shifts between informal and formal help, and/or the increase in use of formal help may signal ways in which the service delivery system responds to changes when caregiver networks cannot meet all of the elder's needs for care. In general, cross-sectional findings suggest that the *need* for services by the older person (usually indicated by health and functional status) is the most consistent predictor of use of formal services, with additional variation sometimes explained by *predisposing* or *enabling* characteristics such as socioeconomic status and number of informal helpers (Coulton and Frost, 1982; Soldo, 1985; McAuley and Arling, 1984; Tennstedt, McKinlay, Sullivan and D'Agostino, 1988). These studies have used a variety of outcome variables, ranging from specific types of service such as nursing services, homemaker assistance, physician visits to summary measures of any service use, but the primacy of the need variables is consistent.

The Anderson et al. model originally focused on attributes of the older person only. In an important contribution, Bass and Noelker (1987) recently broadened the conceptual framework to argue that informal support systems, i.e. family caregivers, also influence service use. Family caregivers influence the elder's use of services directly through their gatekeeper or case management role, indirectly through their influence on perceived need for help, and also through the ability of other network sources to relieve the primary caregiver who is overburdened (Bass and Noelker, 1987). Bass and Noelker's extension conceptualized caregiver need in terms of stress levels. We focus instead on the two types of caregiver burden as indicators of caregiver need. We assume that caregivers who experience higher burden at time one will be more likely to turn to formal services as a relief from care demands and responsibilities. The implication is that caregivers become "burned out" or exhaust their own resources before turning to formal services in response to increased disability in the frail family member.

This chapter addresses three research questions: 1) How stable are the formal task support networks over a two-year period? 2) To what extent, does the burden/ strain of the primary caregiver affect changes in the structure of care networks, all other things being equal? 3) What is the nature of the relationship between caregiver burden and the interface between formal and informal care? Following a description of stability and change in the size and intensity of help of informal, we propose and analyze a model of the effect of primary caregiver burden on changes in the informal network structure. In addition, we examine briefly the interrelationship between burden, changes in the number of informal helpers and changes in the number of formal helpers.

Sample and Measures

The analysis of use of formal services is based on the longitudinal sample of 615 cases described in Chapter 4. A subsample of 196 cases, representing those who had used formal services in either 1982 or 1984, is examined in analyses of change in the number of formal person days. This restriction was made because users of formal help differ in key characteristics from non-users, and changes in level of formal help can only be adequately described within this subpopulation of users.

Formal support is measured by two indicators: the number of formal helpers (paid helpers or persons from an organization who provide ADL or IADL assistance), and amount of formal help provided measured by the sum of the days of help provided by all formal helpers of a specific elder. Use of formal services represents the interaction of the formal system of care with the informal system, because all the elderly in this sample have an informal caregiver at time one.

Plan of Analysis

The analysis begins with a description of change and stability in the use of formal helpers and the number of person days of formal help received by the frail older person, and investigation of bi-variate correlations with caregiver and frail older person characteristics. Our analysis of the effect of caregiver burden on change in the formal helper network is a two-step process. We first estimate an hierarchical logistic regression model determining the contribution of burden to use of formal helpers in 1984. Because only approximately 25 percent of the frail older persons used any formal helpers, the amount of help provided is estimated only on the subsample of respondents who reported use of formal helpers in either time period. The second step thus focuses on the contribution of burden to the amount of formal help received by these respondents. This strategy is similar to that used by McAuley and Arling (1984) and Bass and Noelker (1987).

Results

Change in Formal Helper Networks

Formal helpers are used infrequently by older persons. In 1982, only 19.4 percent (182) of the total sample (n=940) and 16.1 percent (99) of those living in the community in both time periods with valid data (n=615) used any formal helpers. This percentage increased to 27.3 (168) in 1984. The concept of a network of formal helpers is a misnomer, since in most instances, only one formal helper was involved. In 1982, among the 99 older persons with formal helpers, only 18 percent (18) had two or more formal helpers. In 1984, among the 168 persons with formal helpers, 29 percent (49) had more than one formal helper. The number of person days of help ranged from 0 to 15 in both 1982 and 1984.

Use of formal helpers in 1982 was associated with mortality and nursing home placement: among the total initial sample of 940 frail elders, 12.5 percent of those who used formal helpers in 1982 moved to nursing homes by 1984 and 31.5 percent were deceased, compared to 6 percent institutionalized and 22.5 percent deceased of those who did not use formal help (chi-square= 118.6, df.3, p.=.000).

Table 5-1 presents the statistics on change in use of formal help and in the number of person days of formal help. We examine change in number of formal helpers among the subsample as a whole and among only those who used formal services at any time in 1982 or 1984 (n=196). We include this latter group to assess if change among the formal service user group follows the same pattern as the larger sample who include so many non-users.

Among the sample of community living older persons, the distribution of change scores in number of formal helpers shown significant difference in the use of formal helpers, although 75 percent had not change (Table 5-1). Changes that did occur were most likely to be increases in the number of formal helpers from 0 to 1. We see greater instability in use of formal helpers when we focus only on those who used formal help in either time period (n=196). Only 23 percent maintained the same number of helpers, and approximately 60 percent increased helpers. Most of this increase results from the shift from no help to one formal helper. The results of the t-test indicate that this change reflects actual differences between the two time periods, not sampling error. The low negative correlation coefficient (-.102) further suggests that use of formal helpers at Time 1 is a minimal source of use of formal helpers at Time 2. We speculate that the choice of formal help is a time-specific decision, made in response to a specific crises or need of either the frail older person or the primary caregiver, or changes in Medicare policies, rather than a general pattern of care provision. Although the Q^2 statistic suggests little overall change, that which does occur among users (n=196) is mainly individual-level shifts.

The pattern of change in amount of formal help received mirrors the pattern in use of services just described. Only 20 percent (39) received the same level of help at both time periods. The increase in days of help was statistically significant at the population level. The relatively low correlation coefficient (r=.234) suggests, however, that the level of formal help provided in 1984 is relatively independent of previous levels of use. This pattern of time independence of use of formal help differs markedly from the greater stability and continuity over time seen within the informal network.

Characteristics of the Primary Caregiver, the Older Person, and Changes in the Formal Helper Network

A preliminary step to the multi-variate analysis of change is bi-variate examination of changes in use of formal helpers over the two year period by specific characteristics of the primary caregiver and the older person. Table 5-2 presents the proportion of older persons who used formal helpers in 1982 and the direction of change in level of use in 1984 by selected characteristics of the primary caregiver. In view of the relatively small number of formal helpers used, we examined only the dichotomous measure of formal helper use. Oneway analysis of variance tested the statistical significance within each category.

Significant differences in use of formal helpers in 1982 were associated with caregiver gender, age, and education. Persons with male caregivers, youngest and oldest caregivers, and caregivers with higher education were most likely to include formal helpers in their helper network. Caregiver age and education, but not gender, was also associated with a change in use of formal helpers. The bimodal effect of age continued, as those with the youngest and oldest groups of caregivers evidenced the most change in both directions, but with an overall greater tendency by youngest and oldest caregivers to increase use of formal helpers rather than decrease. Similarly, those with highly educated caregivers were most likely increase help. There were no significant differences in 1982 by either type of burden, but high personal burden of the primary caregiver was associated with a significant increase in use of formal helpers in 1984. Interpersonal burden was not associated with change. Caregivers and service delivery systems alike are more likely to perceive that formal helpers may be less helpful in relieving relationship-based strains. Alternatively, formal help may be available for specific personal care activities, but not for long-term supervision.

The socio-demographic characteristics of the frail older person were linked to use of formal helpers in anticipated directions for age and education (Table 5-3). Older persons and those with higher education were more likely to have formal helpers and more likely to increase their use of formal help over time. Contrary to other research, however, gender, race, and marital status had no effect of formal service use. Other studies have suggested that males, whites and the non-married are more likely to use formal services (Horowitz, 1985). Increased disability in ADL level is associated with increases in the use of formal helpers. Changes in IADL status did not have any effect, however, perhaps because the high proportion of those with no change in IADL status were already at a higher level of need and receiving some service help. Since most service-delivery programs respond only to physical care needs, the lack of effect of IADL needs on use of formal helpers also may reflect ligibility requirements of the service delivery system.

We examined the association between caregiver and older person characteristics with change in the amount of formal days of help, using the sub-sample of 196 persons. We found, however, that there were no significant differences by any attribute of the caregiver or frail person (data not shown).

Table 5-4 confirms that in 1984 persons with higher indicators of disability on all measures of health, excluding number of chronic conditions, were more likely to use formal helpers. Among those who used formal help in 1984 (n=168), only higher levels of ADL and IADL disability were significantly associated with higher levels of days of help. These findings suggest that the criteria for service delivery focus on functional disability, rather than other health needs, but also suggest restricted variability in number of days of help With the exception of those with low ADL and IADL levels of disability, the average days of help hovered between 3.2 to 3.8 days, a much lower level of help than that provided by the informal network.

The Effect of Caregiver Burden on Changes in Use of Formal Help

Our model of determinants of formal help is organized according to the Bass and Noelker (1987) adaptation of the Anderson and Newman model (1973). This approach includes caregiver characteristics within each model component. Since we are estimating a longitudinal model of the effects of caregiver burden on change in formal helper use, our analytic model differs from Bass and Noelker in one key respect. We emphasize use of formal services and caregiver burden as the primary predisposing variables, before the more typical demographic attributes are taken into account, because prior use of formal services indicates that other knowledge and accessibility barriers have been overcome. Since we are most interested in understanding the effect of burden on use of formal services, we use an hierarchical regression approach, in which changes in the coefficient of burden can be compared as other predisposing, enabling, and need variables are entered into the equation. Thus, predisposing and enabling variables are viewed as antecedent factors that influence the need for services.

Use of formal services is a dichotomous variable, and as such, requires a different analytic strategy than ordinary least squares regression analyses or structural equation modeling. Logistic regression is a suitable technique for predicting a dichotomous dependent variable, generating maximum likliehood estimates based on an assumed functional form represented by an S-shaped or logistic curve. This functional form implies that when certain predictors approach their upper or lower limit, the outcome is almost certain, limiting the effect of other variables on that outcome (Soldo, 1985). For example, if caregiver burden or elder functional disability is very low, there is little likelihood that use of formal services will occur, regardless of financial resources, or number of other helpers, or be viewed as a formal service, e.g. cleaning help. At moderate ranges of need, however, predisposing and enabling variables may take on more importance.

Preliminary analyses revealed multi-collinearity among three groups of predictor variables that could affect the stability of results (See the correlation matrix in Table 5-5). As a result of the large proportion of spouse caregivers in the sample, there was high intercorrelation among the relationship of the caregiver, the sex of the impaired older person, and the older person's age. We thus dropped elder's sex as an predisposing predictor. ADL and IADL levels of need were also intercorrelated. We retained both indicators, however, in the model since they represent different types of limitations and service needs, the stronger effect of physical limitations masked some of the predictive ability of instrumental activities of daily living limitations when that variable was entered alone. We also found in preliminary analyses that the correlation between personal and interpersonal burden masked the significant effect of personal burden on use of formal services. Although each burden variable used alone had some effect on use of services prior to entering the need variables into the model, the effect of personal burden was consistently stronger than interpersonal burden (as indicated by chi-square values), yet its effect was markedly diminished when both burden variables were included. We concluded that relationship burden had little effect on use of formal services, especially when need for services was taken into account, and omitted this variable in the final model to concentrate on understanding the effect of personal burden.

The final model, presented in Table 5-6, includes twelve predictors of formal service use. Predisposition to use of formal services is represented by the older person's age, race, and relationship of primary caregiver. We anticipate that older frail persons, whites, and those with adult child caregivers are more likely to continue or increase use of formal services. Enabling variables include educational achievement of the caregiver, per capita family income level, and number of informal helpers. We assume that the educational level of the caregiver will have more influence on service use than the educational level of the older person. Primary caregiver often act in a case management or advocacy role in the purchase of services and thus their educational level and experience with formal organizations will have primary influence on the service use. The number of informal helpers is a resource such that more informal helpers may substitute for the need for formal help with task assistance. Indicators of need include the level of ADL impairment, level of IADL impairment, the number of chronic conditions, and prior hospitalization. We expected prior hospitalization to be an especially strong indicator of need for two reasons. First, hospitalization is a formal service, and potentially increases the older person's and caregivers knowledge of the formal service system. Second, in many states, use of financially covered home health services is linked to a period of hospitalization.

Logistic regression coefficients can be interpreted as the effect of each predictor variable on the probability of using formal services. The individual Chi-square value provides an indicator of the relative contribution of each variable to the total model. Comparison of the difference in the log-likelihood model Chi-square values in the hierarchical set of logistic regression s provides a test of the increment in fit associated with each variable set.

The first-stage of the logistic analysis of the probability of using formal helpers controls for the effect of prior use, the largest predictor in all the models, and shows that personal cargiver burden made a significant net contribution to use of formal helpers in 1984. Model 2 indicates that the effect of burden was not mitigated by other predisposing variables, although older age of the frail person significantly increases the probability of formal help. Enabling variables did not significantly increase the use of formal services in Model 3, and the effect of the other variables remains unchanged. Model 4 incorporates the elder's health and functional status, typically the strongest determinants of use of formal help. Controlling for prior use of formal helpers and other model variables, level of ADL disability and hospitalization of the older person become the most important predictors of change in use of formal helpers. The effect of IADL disability is smaller, partly as a result of confounding with the ADL measure. Age of the older person, family income, and size of the informal helper network also significantly affect the probability of use of formal helpers, although the size of the contribution is small. The association between number of informal helpers and formal helpers is negative, suggesting that extensive informal networks are associated with reduced use of formal assistance for maintenance in the community, when physical need is taken into account.

The risk of use of formal helpers, i.e. the regression coefficient, can be expressed as adjusted odds ratio. Those with prior use of formal helpers are nine times more likely to use service again. An increase of five years in the frail person's age results in a risk 1.3 time greater. Adding one informal helper to the network reduces the risk of use of formal helpers, as seen in the odds ratio of .79.

Even after the level of need is controlled, personal burden of the primary caregiver continues to contribute to use of formal helpers, albeit at a reduced level (p <.07). Our previous research based on cross-sectional data shows that personal burden is influenced by the functional level and health status of the older persons (Miller, McFall, and Montgomery 1988). Thus, the continued influence of primary caregiver personal burden on the increase in use of formal helpers is striking and supports the argument that family needs as well as older person needs determine use of formal sources of help.

The Effect of Caregiver Burden on Number of Person Days of Help

Analysis of determinants of change in number of formal days applies only to that subsample that used formal helpers at either time period, approximately 30 percent of the longitudinal sample. By omitting those with no formal contact, we consider that different processes may distinguish between employment of formal resources and the actual level of help provided (Bass and Noelker, 1987). Although we use the same model of predictor, enabling, and need variables, we expected that elder need would be an even stronger factor determining the amount of formal help received. Analysis of the bivariate association between characteristics of the caregiver and frail older person and number of person days revealed no significant associations. Only previous hospitalization had any relationship with number of formal days of help (data not shown).

Table 5-7 presents the model of change in number of formal days of help. Once again, because of multicollinearity, we omitted the older person's sex and interpersonal burden from the model. Preliminary analyses confirmed that these variables did not contribute any explained variance in amount of formal help. Model 1 controls for the effect of previous number of days of help and shows that personal cargiver burden made a significant net contribution to use of formal helpers in 1984. Model 2 indicates that the effect of burden was not mitigated by other predisposing variables. The enabling variables significantly increased the variance explained in amount of formal help in Model 3, although personal burden continued to make an important contribution. In comparison to the predictions of use of formal help, enabling variables have an independnet effect of level of help recieved, even before need in introduced. Level of help was related positively to per capita income, but negatively to caregiver's education. This latter finding is contrary to expectation and difficult to interpret, especially since income and education are positively related to each other. We have assumed that those with higher financial resources not only may be able to pay for services, but are also more sophisticated in knowledge of how to attain services. But other dynamics may be operating, in which those caregivers with lower education may be more likely to be eligible for agency services or Medicaid reimbursements.

Model 4 incorporates the elder's health and functional status. Personal burden no longer contributes significantly to amount of help received when health needs are introduced into the model. The major predictors of change in level of help received are caregiver education, per capita income, and concurrent level of ADL limitations. This model explains 15 percent of the variance in the number of personal days of formal help. Although this percentage is comparable to that found in the literature, clearly a better specification of the model is needed.

Relationship Between Use of Informal and Formal Care

An important policy question continues to be that of the relationship between use of informal and formal care. Policy-makers dominated by the const-containment concerns fear that provision of more formal services will minimize the currently unpaid care contributions of family members, whereas policy-makers concerned about caregiver burnout and the subsequent effect on institutionalization argue that provision of more formal services will supplement family care in ways that sustain the frail older person in the community. Noelker and Bass (1989) describe four possible models of informal-formal linkages: complementary (formal and informal services provide assistance with different tasks); supplementary (formal services assists with tasks informal system also provide); substitution (formal system meets all care-recipients needs); and kin independence (no help from formal services). Our study results thus far point to a predominant model of kin independence, since relatively few older persons were receiving formal services in light of the high level of disability. Because we are not analyzing task patterns of help, we cannot adequately distinguish between patterns of complementary, supplementary, or substitution of helper activities.

In line with our focus on the effects of caregiver burden, however, we can examine the change in number of informal helpers by the change in number of formal helpers by level of personal and interpersonal burden (Table 5-8). Note that we cannot identify the sequence in which these changes occurred during the two year period. Among those with low personal burden in 1982, there was no relationship between change in informal helpers and change in formal helpers, as the 12-15 percent increase in formal helpers was evenly distributed across the three informal change groups (Table 5-8A). Among those with high personal burden, however, there was a significant association. Of those with high personal burden, an increase in use of formal helpers was found: 24.6 percent of older persons who decreased the number of informal helpers, 12.6 percent of those who increased number of informal helpers and 30.8 percent of those who did not change the size of their helper network. There was no association between amount of change in informal or formal helpers by level of interpersonal burden (data not shown).

These findings may be interpreted as indirect evidence that some supplementation and substitutional effects occur over time in response to caregiver's personal burden. Supplementation may be observed by those with no change in informal helpers who added formal services in response to increased need by the frail older person under conditions of high personal burden. Substitution may be occurring between those who decreased the number of informal helpers in their network, while increasing the number of formal helpers.

Conclusion

Formal networks were used in a minimal fashion by frail older persons and their caregivers, but did expand in use over the two year period among the longitudinal community sample. There was a general trend to increased use in formal help over time, although over 3/4th of the sample did not use any formal helpers at any time during the study period. The use of formal services was fairly unstable, and appeared to respond more to time-specific needs than the continuity in care presented by informal care network over time. Increased functional disability during the two year period, and poorer health status of the frail older person in 1984, represented by ADL and IADL disability and cognitive problems were related to larger size networks and higher levels of care in both informal and formal helper networks.

Sociodemographic characteristics of the caregiver and frail older person were associated with the increased use of formal help, but the amount of increase was small. Logistic regression results indicated that personal burden influenced changes in use of formal services two years later, even after controlling for functional status. Among those who used any kind of formal service, personal burden had no effect on the level of formal help, once functional status was taken into account. Among those with high personal burden, evidence of shifts in the relationship between change in the informal and formal network were observed, suggesting both supplementation and substitution effects.

TABLE 5-1. Change in Formal Helper Network, 1982-84

	Formal Helpers (n=614)		Formal Helpers (n=196)[a]	
	n	**%**	**n**	**%**
A. CHANGE IN NUMBER OF FORMAL HELPERS				
DECREASE				
-2	8	1.3	8	4.1
-1	25	4.1	25	12.8
NO CHANGE				
0	464	75.4	45	23.0
INCREASE				
1	93	15.1	93	47.4
2 to 7	25	4.0	25	12.8
MEAN (sd)	.179 (.671)		.561 (1.10)	
T-TEST T-VALUE	-6.61, (p<.001)		7.17 (p<.001)	
PEARSON'S CORRELATION	.407		-.102	
Q^2 PARTITIONED	.119+.032		29.33 + .019	
	Person Days of Help (n=196)[a]			
	n		**%**	
B. CHANGE IN NUMBER OF PERSON DAYS OF FORMAL HELP				
DECREASE				
-1 to -7 days	43		22.0	
NO CHANGE				
0	39		19.9	
INCREASE				
1 to 4 days	76		38.7	
5 to 15 days	38		19.4	
MEAN (sd)	1.50 (3.36)			
T-TEST T-VALUE	6.27 (p <.000)			
PEARSON'S CORRELATION	.232			
Q^2 PARTITIONED	11.29 + 2.25			

a. This subsample represents all older persons who used formal help in either 1982 or 1984.
b. Because of the lack of change, the Q2 statistic was not computed.

TABLE 5-2. Percent Use of Formal Help in 1982 and Amount of Change by 1982 Characteristics of the Primary Caregiver (n=615)

Caregiver Characteristics	Use of Formal Helpers, 1982 (Percent)	Change in Use of Formal Helpers		
		Decrease	No Change	Increase
RELATIONSHIP				
Spouse	14.5	4.8	77.7	17.4
Adult child	18.6	6.2	71.9	21.9
SEX				
Male	22.5 *	7.4	72.5	20.1
Female	12.9	4.4	76.9	18.7
AGE				
14-55	21.5 *	8.9	69.6	21.5 *
56.64	12.8	3.5	80.9	15.6
65-74	10.8	3.6	80.3	16.1
75 and over	24.1	6.9	66.4	26.7
EDUCATION				
< high school	12.9 *	4.4	80.0	15.6 *
High school	17.1	6.3	74.1	63.5
> High school	24.3	7.0	63.5	29.6
PERSONAL BURDEN				
Low	15.5	6.3	79.9	13.8*
High	16.7	4.5	71.1	24.4
INTERPERSONAL BURDEN				
Low	17.3	6.3	76.6	17.1
High	14.1	3.8	73.5	22.6

* Probability < .05

TABLE 5-3. Percent Use of Formal Help in 1982 and Amount of Change by 1982 Characteristics of the Primary Caregiver (n=614)

Older Person Characteristics	Use of Formal Helpers, 1982 (Percent)	Change in Use of Formal Helpers		
		Decrease	No Change	Increase
SEX				
Male	23.7	4.5	78.0	17.5
Female	29.7	5.9	73.8	20.3
AGE				
65-69	14.4*	5.3	83.3	11.4*
70-74	20.6	7.1	79.4	13.5
75-79	35.3	5.2	69.8	25.0
80 plus	35.8	4.2	70.8	25.0
EDUCATION				
< High school	13.3*	4.3	79.3	16.4*
High school	17.4	6.3	76.8	16.9
> High school	25.7	8.6	58.6	32.9
RACE				
Non-white	18.5	7.4	76.5	16.0
White	15.7	5.1	75.3	19.7
1982 MARITAL STATUS				
Not married	18.6	5.9	71.5	22.6
Married	14.6	5.1	78.1	16.8
CHANGE IN ADL LEVEL				
Decline	a	7.4	79.2	13.4*
No change		5.9	73.9	20.2
Increase		2.6	73.0	24.5
CHANGE IN IADL LEVEL				
Decline	a	4.9	81.3	13.8.
No change		3.4	67.3	29.3
Increase		7.0	74.9	18.1

a. Not applicable

* = Probability <.05

TABLE 5-4. Percent Distribution of Use of Formal Help and Mean Level of Help Received in 1984 by Health Characteristics of the Frail Older Person in 1984			
Older Person Characteristics	**Use of Formal Help (n=614)**	**Person Days of Help (n=168)**	
	Percent	**Mean**	**St. Deviation**
ADL LIMITATIONS			
Low	12.9[a]	1.3	1.8[a]
Moderate	28.6	3.1	2.8
High	43.1	3.8	3.1
IADL LIMITATIONS			
Low	12.8[a]	1.27	1.38
Moderate	24.8	3.55	3.02
High	42.1	3.8	3.11
1984 PROXY FOR COGNITIVE EXAMINATION			
No	23.9[a]	3.16	2.9
Yes	33.0	3.60	3.2
HOSPITALIZED PREVIOUS YEAR			
No	21.3	3.3	3.3
Yes	37.8[a]	3.4	2.8
CHRONIC CONDITIONS			
0 - 2	26.0	3.25	2.9
3 - 7	28.7	3.51	3.1

a. Probability of Chi-square values < .001
b. Probability of Chi-square values < .05

TABLE 5-5. Correlation Matrix of Use of Formal Service Variables (N=615)

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
1	1.00															
2	.44[b]	1.00														
3	.05	.18[b]	1.00													
4	-.02	.08	.54[b]	1.00												
5	.01	.06	-.02	-.12[a]	1.00											
6	-.12[a]	-.06	.14[b]	.15[b]	-.26[b]	1.00										
7	-.03	.02	.00	-.06	.13[a]	-.09	1.00									
8	.12[a]	.19[b]	.04	.12[a]	.03	.20[b]	-.03	1.00								
9	.05	.05	.01	.14[b]	-.70[b]	.21[b]	-.11[a]	.49[b]	1.00							
10	.12[a]	.11[a]	.04	.08	-.27[b]	.09	.17[b]	.05	.21[b]	1.00						
11	.10	.11[a]	-.02	-.06	.08	-.12[a]	.27[b]	-.08	-.12[a]	.30[b]	1.00					
12	.02	-.02	.03	.08	-.07	.04	-.11[a]	.16[b]	.18[b]	-.04	-.12[a]	1.00				
13	.16[b]	.32[b]	.26[b]	.12[a]	.04	-.00	-.00	.17[b]	.03	.11[a]	.01	.14[b]	1.00			
14	.13[a]	.27[b]	.35[b]	.27[b]	-.07	.18[b]	-.09	.33[b]	.21[b]	.08	-.09	.23[b]	.59[b]	1.00		
15	.00	.08	.20[b]	.11[a]	-.02	-.02	-.01	-.12[a]	-.04	-.02	-.02	.08	.22[b]	.15[b]	1.00	
16	.11[a]	.18[b]	.06	-.01	.08	-.04	.00	-.06	-.09	-.00	-.02	.05	.09	.06	.06[b]	1.00
Mean	.16	.27	1.94	1.33	64.20	.64	.87	78.51	1.39	10.13	3.79	1.77	2.51	5.69	2.49	.38
SD	.37	.45	1.82	1.26	11.94	.47	.34	7.76	.49	3.60	1.60	1.16	2.04	3.07	1.15	.49

VARIABLES:
1=Use of formal services in 1982
2=Use of formal services in 1984
3=Personal burden
4=Interpersonal burden
5=Caregiver age
6=Caregiver sex
7=Elder sex
8=Elder age
9=Caregiver relationship
10=Caregiver education
11=Elder per capita family income
12=Number of informal helpers
13= Elder Physical ADL limitation
14=Elder instrumental ADL limitation
15=Number of chronic condition
16=Previous hospitalization

PROBABILITY:
a. <.01
b. <.001

TABLE 5-6. Logistic Regression of Use of Formal Helpers, 1984, on 1982 and 1984 Predisposing, Enabling, and Need Factors

	Model 1 1982 Need		Model 2 Predisposing		Model 3 Enabling		Model 4 Elder Need	
	B	**Chi-Sq.**	**B**	**Chi-Sq.**	**B**	**Chi-Sq.**	**B**	**Chi-Sq.**
1982 NEED								
Use of formal helpers	2.43[a]	90.2	2.40[a]	84.7	2.34[a]	78.8	2.22[a]	63.1
Personal burden	.23[a]	17.2	.22[a]	16.1	.23[a]	16.5	.12[d]	3.3
PREDISPOSING								
Race (1=white)			.29	.83	.04	.02	.07	.03
Elder's age			.06[a]	13.2	.06[a]	15.4	.05[a]	8.7
Relationship of caregiver (1=adult child)			-.28	1.3	-.31	1.4	-.15	0.3
ENABLING								
Caregiver education					.03	.92	.01	.05
Per capita income					.10	1.97	.15[c]	4.0
Number of informal helpers					-.13	1.79	-.23[c]	4.9
ELDER'S NEED								
ADL limitations							.24[a]	12.5
IADL limitations							.09[d]	3.4
Chronic conditions							.05	.3
Hospitalization (1=yes							.79[a]	12.1
INTERCEPT	-1.951		-6.48		-7.16		-7.61	
LOG LIKELIHOOD RATIO	594.73		579.6		572.62		520.21	
MODEL CHI-SQUARE	122.01		137.09		142.84		189.46	
DEGREES OF FREEDOM	2		5		8		12	

a. Prob < .001
b. Prob < .01
c. Prob < .05
d. Prob < .10

TABLE 5-7. OLS Regression of Number of Formal Helper Days, 1984, on 1982 and 1984 Predisposing, Enabling, and Need Factors*

Variables	Model 1 1982 Need		Model 2 Predisposing		Model 3 Enabling		Model 4 Elder Need	
	Coeff.	Beta	Coeff.	Beta	Coeff.	Beta	Coeff.	Beta
1982 NEED								
Number of formal helper days	.29[a]	.22	.30[b]	.23	.32[a]	.24	.31[a]	.24
Personal burden	.31[b]	.20	.30[b]	.19	.26[c]	.17	.09	.05
PREDISPOSING								
Race (1=white)			-.04	-.00	-.01	-.00	.17	.02
Elder's age			.04	.11	.05	.12	.03	.08
Relationship of caregiver (1=adult child)			-.21	-.03	-.03	-.01	.08	.01
ENABLING								
Caregiver education					-.17[a]	-.21	-.19[a]	-.23
Per capita income					.27[c]	.15	.30[c]	.17
Number of informal helpers					-.12	-.05	-.18	-.07
ELDER'S NEED								
ADL limitations							.29[c]	.19
IADL limitations							.13	.11
Chronic conditions							.04	.02
Hospitalization (1=yes							.27	.04
CONSTANT	1.77		-1.43		-.85		-1.60	
ADJUSTED R^2	.083		.079		.115		.164	

* N=192, subsample of those who used formal helpers in either 1982 or 1984. 4 cases with missing values not included

a. Prob < .001
b. Prob < .01
c. Prob < .05

TABLE 5-8. Change in Number of Informal Helpers 1982-1984 by Change in Use of Formal Help by Level of Personal Burden

Outcome	Change in Number of Informal Helpers					
	Decrease		No Change		Increase	
	n	%	n	%	n	%
A. LOW PERSONAL BURDEN (n=304)						
Decrease formal help	6	7.7	9	5.9	4	5.5
No use formal help	62	79.5	121	79.1	60	82.2
Increase formal help	10	12.8	23	15.0	9	12.3
Total	78	100.0	153	100.0	73	100.0
Likelihood Ratio Chi-square	.761, df 4, p=.94					
B. HIGH PERSONAL BURDEN (n=311)						
Decrease formal help	3	4.6	6	3.8	5	5.7
No use formal help	46	70.8	104	65.4	71	81.6
Increase formal help	16	24.6	49	30.8	11	12.6
Total	78	100.0	153	100.0	73	100.0
Likelihood Ratio Chi-square	10.98, df 4, p=.026					

VI. THE EFFECT OF CAREGIVER BURDEN ON HOSPITAL USE OF FRAIL OLDER PERSONS

The impact of caregiver burden on hospital use, the most costly component of medical care, has not been examined. We anticipated that the impact of caregiver burden on hospital use would be less than its impact on more discretionary types of care or on use of long-term care services, since need for medical care typically drives use of hospitals in populations of community (Wolinsky, 1978; Wolinsky and Coe, 1984) and disabled (Wan and Arling, 1983) elderly. These studies focus on individual behavioral determinants of hospital use and do not take into account the changing social, organizational, and regulatory environment within which hospitals operate.

Within the context of the contraction of length of hospital stay, resulting in part from the shift to prospective reimbursement, the availability and willingness of family members to provide care for recuperating patients is a factor in discharge planning. In 1984, between 3 and 4 million days of care were estimated to have shifted from the hospital to the community and home (Abel, 1987). Thus, family care characteristics may affect the use or volume of hospital services by functionally disabled elderly in ways analogous to their effect on other formal services (Bass and Noelker, 1987).

The behavioral model of use of medical care, or the Anderson-Newman model has dominated sociological and gerontological research on the determinants of hospital use by the elderly. This model views service use as influenced by predisposing, enabling, and need factors (Anderson and Newman, 1966). Generally, the variance explained in use or volume of hospitalization is quite small, ranging in studies reviewed from 6.1 percent (Wan and Arling, 1983) to 13 percent (Wolinsky et al., 1983). The low explanatory value of applications of the behavioral model has been attributed in part to faulty or inaccurate measurement of basic concepts (Wolinsky and Coe, 1984). In addition, more fundamental criticisms of the model have been made (e.g., Mechanic, 1979). Nevertheless, model innovations that better address the prediction of use of services have not been proposed.

Although physicians act as the primary gatekeepers in hospitalization, family caregivers may contribute to the decision in several respects. First, they may participate in the decision that symptoms or conditions of the frail elders require medical attention and care that cannot be provided in the home. A burdened caregiver may be quicker to encourage the use of medical and hospital services. Second, as stated above, family members contribute to the volume of services through their participation in discharge planning. For example, burden may contribute to reluctance to facilitate early discharge from the hospital. In Chapter 5, we found that personal burden had a slight influence on the use of formal services and a stronger influence on the extensiveness of formal help provided. Thus, while we are skeptical about the impact of burden on use of hospitalization per se, a better case may be made for an impact of burden on length of stay or the amount of hospital resources consumed as assessed by days of hospitalization.

Sample and Methods

The sample for this chapter is the longitudinal sample of those with community interviews in 1982 and 1984, for which there was complete data on hospitalization (n=605).

We examined three aspects of hospital use: (1) presence of one or more hospitalizations in past 12 months, (2) the number of hospital admissions in the past year, and the number of days of hospital use. The days of hospitalization were assessed for the three most recent hospitalizations in the year preceding the interview.

The independent variables can be categorized according to the behavioral model. Predisposing variables included gender, race, age, whether the subject lived with others or alone, and relationship with the primary caregiver. Enabling variables included per capita family income, supplementary insurance, and having a regular source of medical care. Need is assessed by ADL and IADL limitations, number of chronic condition categories, and prior hospitalization. Personal burden was categorized as a need factor introduced by the caregiver. The majority of these variables were defined in Chapter 2. Subjects were classified as having supplementary insurance if they reported receiving Medicaid, other public assistance including medical care, CHAMPUS/CHAMPVA, or private insurance. Regular source of care was a simple item reporting on the presence or absence of a source of medical care.

Most studies of use of hospitals have been analyses of cross-sectional surveys. In these studies, health status, such as number of chronic conditions or self-reported health, and functional capacity, such as ADL limitations, assessed at the time of the interview are used to explain use of health services occurring in some time interval prior to the interview. Frequently, the utilization measure is taken as a general indicator of frequency or volume of service use. The health status measures are assumed to represent relatively enduring states of health, that would be strongly linked to health status at the time of the decision to seek care.

In this chapter we address the issue of whether caregiver burden is related to use of hospital services when controlling for other predisposing, enabling and need factors. We first examined the bivariate relationships of the three indicators of hospital use and the independent variables. The need factors are assessed using both the 1982 and 1984 interviews. Next, we conducted multivariate analyses using multiple regression. With respect to use of hospital services, we examined separately the set of predisposing and enabling factors, then the 1982 need factors, then the 1984 need factors. A combined regression equation including all terms for which the regression coefficient had $p < .10$ was then estimated. While use of hospital services is a dichotomous variable, almost 40 percent of the sample was hospitalized, and we decided to use ordinary least squares regression rather than more complex techniques. A similar strategy was used with the other indicators, number of hospital admissions and days of hospital care. However, the sample was limited to the 230 subjects who indicated hospital use in 1984. These regressions were repeated using log transformations of number of hospital admissions and days of hospital care to make these dependent variables more nearly normally distributed.

Results

Approximately 38 percent of the subjects interviewed in 1984 reported use of hospitals in the prior year. Of those, 51 percent reported hospitalizations in the 1982 interview as well. Of the 230 subjects reporting hospitalizations in 1984, most had one admission (67 percent), with an additional 23 percent reporting two admissions. The mean number of admissions was 1.54, with standard deviation of 1.01. The maximum number of admissions reported was 6. With respect to number of hospital days, 25 percent of the sample using the hospital reported 5 or fewer days, 50 percent had fewer than 10 days, and 75 percent had 18 or fewer days. The mean value was 16.9 days, with a standard deviation of 23.9. The maximum number of days reported was 180. Log transformations made the distributions of these two variables more normal.

Table 6-1 summarizes the bivariate analyses of selected predisposing, enabling, and need variables with hospital use, number of admissions and number of hospital days. Analyses for number of admissions and number of days is limited to the 230 subjects with hospital episodes in the year prior to the interview.

Only three variables are significantly associated with hospitalization: indicating one or more hospital episode in the 1982 interview, number of chronic conditions in 1984, and having a spouse for primary caregiver. ADL limitations in 1982 and 1984 were also linked to hospitalization, although the relationships were not statistically significant. While chronic conditions are relatively stable, we should note that this measure is based on condition checklists, and that certain of the items are based on whether manifestations of chronic conditions occurred in the past year. Hence, the number of chronic conditions in 1984 may be as much a reflection of the episode of hospitalization, e.g. for a heart attack in the past year, as an assessment of enduring chronic conditions.

Number of admissions was significantly related to number of chronic conditions in 1984, and having no regular source of medical care. Number of admissions varied by level of personal burden (p = .11) and ADL limitations in 1984 (p = .12), although these tests were not statistically significant.

Days of hospitalization differed significantly only for ADL limitations in 1982 and 1984. Interestingly, this measure of resource consumption did not form a gradient. In 1982, the big difference appeared to be between those with low levels of limitations who had fewer days and those with moderate and severe limitations. In 1984, those with moderate levels of limitations used more hospital days than the other two categories. In addition, levels of personal burden ($p = .07$) and chronic categories in 1984 ($p = .06$) differed somewhat on number of hospital days.

As a preliminary stage of the multivariate analysis, hospitalization was regressed separately on the set of enabling and predisposing variables, the 1982 need variables, and the 1984 need variables. Variables with regression coefficients having $p < .10$ were then included in a summary regression model. Five variables were thus identified: regular source of care, personal burden, number of chronic conditions, prior hospitalization, and relationship of primary caregiver.

Table 6-2 presents standardized and unstandardized regression coefficients, standard errors, and the coefficient of determination or R-square of these five variables regressed on reports of hospitalization. Report of hospitalization in 1984 was most strongly related to prior hospitalization. In addition number of chronic conditions and having a spouse primary caregiver were positively associated with use of hospitals. Personal burden and having a regular source of care were not linked to use of hospitalization when controlling for other variables in the model.

The same general procedure was followed for number of admissions and number of hospital days on the sample of subjects with hospitalizations reported in 1984. None of the resulting regression equations had significant overall F-tests, making interpretation of individual regression coefficients meaningless. These analyses were repeated using a log transformation for the dependent variables, with essentially the same results. With respect to our primary research question, caregiver burden can be said to have no significant impact on volume of admissions or hospital days.

Conclusions

It is clear that caregiver burden plays little role in the hospitalizations of those disabled subjects remaining in the community over a two year period. Our examination of this issue considered variables similar to those used in prior applications of the behavioral model of health service use. One potential limitation of our assessment is that it did not take into account subjects who were in the community for a portion of the reporting period, 1983-1984, who later died or were institutionalized prior to the 1984 interview.

Given the behavioral model perspective on hospitalization, it appears unlikely that even methodological refinements will result in the demonstration of a sizeable role for caregiver burden in the vast majority of hospitalizations. Furthermore, we may have reached the limits of the ability of the behavioral model to explain use and volume of hospital services. The explanatory power of the behavioral model is influenced by two characteristics of studies: (1) the level of discretion in the response to illness and (2) amount of variation in the study population. Studies that examine responses with high discretion, for example, bed disability days, which is largely a decision of the individual perhaps in consultation with other family members have better explanatory power. The use of physician services or use of preventive services also have been explained in multivariate analyses better than use of hospital services (Mutran and Ferraro, 1988). With respect to variation within the population, we note that predisposing and enabling factors have been more influential in general population studies in which such characteristics vary widely, than in studies of the elderly. Among the elderly, need factors have been found to be almost the sole influence of health service use (Wan and Arling, 1983).

In this study, like other studies of the elderly, predisposing and enabling factors had no influence on hospitalization use. In addition to less variation in need among the elderly, at least relative to the general population, we have examined the least discretionary formal service, hospitalization. Barring elective reasons for hospitalization, e.g., cosmetic surgery, we assume that clinical reasons or hospital organization variables dominate in the decision to admit patients to a hospital. While in principal, the Anderson model might be expanded to include more clinical variables such as diagnoses or organizational variables such as fee policy, we regard its strength as pointing to the role of social and economic influences in the use of services.

Our results suggest that continued exploration of caregiver and support system variables either within the context of Anderson model or in the development of other age/illness-specific models of hospitalization may be warranted. The statistical significance of the relationship of the caregiver as an influence on hospitalization suggests that the role of the family in medical decision-making deserves further clarification. We can speculate that frail older persons cared for by spouses may be more likely to be the object of intimate observation than parents cared for by adult children. When this intimate observation is combined with the high stake of the caregiving spouse in the health and well-being of the frail spouse, greater impetus to seek medical care or hospitalization may result. Alternatively, since our measure of personal burden did not cover the health status and well-being of the caregiver spouse, it remain plausible that caregiving spouse would encourage hospitalization as a means of some respite from the daily care activities of an ill spouse.

TABLE 6-1. Hospitalization, Number of Admissions, and Hospital Days in 1984 by Predisposing, Enabling and Need Variables.			
	Hospitalized (N=604) Percent	**Admissions (N=230) Mean**	**Hospital Days (230) Mean**
NEED 1982			
FORMAL HELP 1982			
Yes	50.0	1.67	19.33
No	35.6**	1.51	16.29
PERSONAL BURDEN			
Low	34.6	1.47	13.67
Moderate	37.7	1.41	14.47
High	41.1	1.72	21.50
INTERPERSONAL BURDEN			
Low	36.7	1.47	18.93
High	38.6	1.58	16.01
HOSPITALIZED 1982			
Yes	50.0***	1.64	19.25
No	30.2	1.45	14.61
ADL 1982			
Low	36.8	1.56	16.41
Moderate	38.4	1.45	18.41
High	38.7	1.62	15.96
IADL 1982			
Low	31.9	1.52	9.46
Moderate	42.6	1.57	18.45
High	36.0	1.52	19.38
CHRONIC CONDITIONS 1982			
0-1	34.2	1.46	17.73
2-3	37.1	1.53	16.37
4-6	42.7	1.61	18.07
PREDISPOSING			
SEX			
Female	36.6	1.47	15.65
Male	39.9	1.64	18.70
AGE			
65-69	44.9	1.69	12.90
70-74	34.4	1.37	16.66
75-79	45.7	1.68	20.90
80-84	33.0	1.68	16.10
85+	34.5	1.38	18.56
RACE			
White	38.0	1.54	16.47
Nonwhite	37.5	1.60	20.07
RELATIONSHIP			
Spouse	41.5*	1.57	17.30
Adult child	32.5	1.49	16.22
LIVING ARRANGEMENT			
Alone	31.6	1.44	17.00
With others	38.6	1.55	16.93

TABLE 6-1 (*continued*)			
	Hospitalized (N=604) Percent	**Admissions (N=230) Mean**	**Hospital Days (230) Mean**
ENABLING			
PER CAPITA INCOME			
Low	41.9	1.63	16.88
Medium	38.7	1.53	16.83
High	29.0	1.44	18.15
SUPPLEMENTAL INSURANCE			
Yes	39.2	1.58	17.54
No	34.4	1.43	14.92
REGULAR SOURCE OF CARE			
Yes	38.8	1.52*	17.09
No	23.5	2.25	12.88
NEED 1984			
ADL 1984			
Low	35.3	1.36	12.05*
Moderate	35.0	1.65	22.29
High	43.3	1.64	18.29
IADL 1984			
Low	21.1	1.44	13.69
Moderate	40.9	1.58	15.96
High	39.3	1.57	20.26
CHRONIC CONDITIONS 1984			
0-1	26.4**	1.29*	18.75
2-3	39.0	1.48	14.52
4-6	45.7	1.90	23.65
* Probability < .05 ** Probability < .01 *** Probability <.001			

TABLE 6-2. Regression of Hospitalization in 1984 on Selected Variables.			
	Unstandardized Coefficient	**Standard Error**	**Standardized Coefficient**
Relationship (1=child)	-.081*	.039	-.082
Regular source of care (1=yes)	.102	.089	.048
Hospitalized 1982 (1=yes)	.177***	.040	.178
Personal burden	.004	.011	.013
Chronic conditions 1984	.056**	.017	.133
Constant	.097	.090	
R-square = .07			
Adjusted R-square = .06			
* Probability < .05 ** Probability < .01 *** Probability <.001			

VII. CAREGIVER BURDEN AND LONG TERM CARE POLICY

This study examined the two-year effect of two interrelated dimensions of burden on four policy-related long term care outcomes: nursing home admission, changes in the informal task support network, changes in use of formal helpers, and hospitalization. This examination contained a number of unique attributes:

1. Use of a national probability survey of caregivers linked to a longitudinal survey of frail elders, containing data from both the caregiver's and frail older person's perspectives.

2. Detailed measurement of a multi-dimensional concept of caregiver burden, distinguishing personal and interpersonal components of burden.

3. Inclusion of a range of long-term care outcomes for an heterogenous group of people who are at high risk for these outcomes. In addition, this group contains a high proportion of persons who have been disabled for a considerable period of time, so that we are examining established patterns of adjustment to chronic care, not responses to crises.

4. Longitudinal analyses of the effect of caregiver burden in the context of changing functional limitations.

This chapter integrates our diverse findings and discusses their implications for long term care policy. Our analyses were divided into bivariate and multivariate analyses of a range of caregiver and frail older person attributes with nursing home admission, hospitalization, and change in the informal and formal care networks. We organize our summary of results by general longitudinal effects and results pertaining to burden and other correlates of our major outcome variables. Table 7-1 summarizes the findings of the multivariate analyses in which distinct predictive models were developed for each outcome.

<u>General Longitudinal Effects</u>

- Two-thirds of the baseline sample were community residents two years later; one-fourth had died, and 7 percent were nursing home residents. Males, non-whites, and those with greater ADL limitations had higher mortality rates.

- Approximately 40 percent were hospitalized in each time period. Of those hospitalized, about 50 percent reported hospitalizations at both time periods.

- Informal task support networks show greater stability in composition and size than change, with a slightly higher degree of change in the level of help provided.

Specifically, household size was most stable, followed by slightly more fluctuation in the number of informal helpers, and even more fluctuation in the amount of informal persons days of help.

- Although smaller in scope and use, formal networks had greater instability over the two years, responding more to time-specific needs than the informal care network. There was a general trend to increased use in formal help over time, but over 3/4th of the sample did not use any formal helpers at any time during the study period.

Nursing Home Admissions

- Nursing home admissions were associated with being older, white, more severe ADL and IADL limitations, use of formal helpers, and both types of caregiver burden at the bivariate level.

- Nursing home admissions were predicted by interpersonal burden, use of formal helpers, white race, older age, and higher IADL limitations.

Changes in Care Network

- Sociodemographic characteristics of the caregiver and frail older person were rarely associated with change in network size per se. Personal burden of the caregiver was associated with an increase in days of informal and formal help.

- Increased functional disability during the two year period, and poorer health status of the frail older person in 1984, represented by ADL and IADL disability and cognitive problems were associated with larger networks and higher levels of care in both informal and formal helper networks.

- Those with high levels of personal burden were more likely to report changes in formal helpers in response to changes in informal helpers than those with low levels of personal burden.

- Changes in informal task support networks were predicted by changes in ADL and IADL limitations, but not personal or interpersonal burden.

- Changes in the use of formal services were predicted by personal burden, greater ADL and IADL limitations, prior hospitalization, prior use of formal helpers, fewer informal helpers, older age of the frail person, and higher per-capita income.

Hospitalization

- Hospitalization reports in 1984 were associated with previous hospitalization, number of chronic conditions, and having a spouse caregiver. The number of admissions was associated with lack of a regular source of care and chronic conditions.

- The only significant predictors of hospitalization in 1983-1984 were previous hospitalizations in 1982, the number of chronic conditions of the older person, and caregiver relationship. Neither personal nor interpersonal burden had any effect on hospital use by the frail elderly.

Personal burden, the caregiver's appraisal of limitations in personal actions and activities as a result of providing cue, in many respects reflects the confinement associated with intense care of an disabled person. The most frequently mentioned problems associated with personal burden were experiencing limitations in social and personal activities, emotional strain, and having to provide care when not feeling well. Interpersonal burden, the caregiver's appraisal of selected interpersonal difficulties that disturb established relationship patterns with the dependent care-receiver, reflects both attributes of the care-receiver, e.g. yelling behaviors, and the reaction of the caregiver, e.g. defining it as a problem. The most frequently mentioned problems in interpersonal burden were the older person's forgetting things and yelling or becoming upset.

Each dimension of burden influenced a different outcome. The primary effect of personal burden, when controlling for other relevant variables, was on the use of formal services. Interpersonal concerns about the dyadic relationship apparently play little part in this decision. Rather the link between personal burden and use of formal helpers, especially in the context of increased dependency of the frail older person, suggests that the confinement associated with intense care is handled by bringing in other helpers, if services are available.

The primary effect of interpersonal burden, when controlling for other variables, was on the risk of nursing home admission. Interpersonal burden may reflect weakening of the cognitive and affective bonds that link family members together. Caregivers are facing not only heavy demands of care, but also confront disturbing behaviors that weigh on the relationship and make it difficult to continue to sustain the older person in the community.

Neither personal nor interpersonal burden had an independent effect on changes in the informal task support network or on the likelihood of hospitalization. We suspect that the reasons for this lack of effect differ for each outcome. The overall continuity of care provided by the informal task support network over the two years studied was high, and responsive primarily to changing care needs of the older person. In the absence of greater detail about the underlying processes, we can only speculate that the family members may ration their care involvement in response to definable needs of the frail older person. Additional caregivers are not recruited or do not volunteer in response to the burden of the primary caregiver, independent of the relative's functional limitations. Our analysis of the interdependence of informal and formal helpers suggest that formal helpers introduce greater elasticity into the care network for those who have sufficient financial resources.

The link between caregiver burden and hospitalization was not strongly advanced, and thus were less surprised at the lack of effect found. More surprising was the lack of explanatory value of the rest of our model variables. We conclude that explanation of use of hospital services for the frail elderly should focus more on clinical and organizational variations.

These findings, examined together, suggest possible processes that may underlie long term care outcomes. The driving force appears to be the level of functional disability or capacity for independence presented by the older person. Greater disability is linked to higher personal burden, and to a slightly lesser extent to higher interpersonal burden as well. Greater disability is also linked to nursing home admissions, use of formal service, and to the modicum of change that occurs within informal care networks. When high personal burden is present and functional limitations increase, greater use of formal helpers occurs. Yet, greater use of formal helpers, in conjunction with interpersonal burden is also linked to increased likelihood of nursing home admissions. We suspect that these processes are not strictly sequential, but form various configurations according to individualized combinations of caregiver, frail older person, and family network characteristics.

Throughout our analyses, we have been struck by the continuity of care provided by the informal care network, and the relative isolation from assistance from external sources of help beyond the family. We assume that the normative obligations of family support, the enduring affective bonds, and history of past caring relationships underlie this durability and stability. Within this study, we could not address either the perceptions of options or the actual availability of services that may alleviate some of the burdens of care associated with this durability. Nor could we identify barriers to use of services, even though studies such as Montgomery and Borgatta (1989) show that such barriers exist. To use an engineering systems analogy, we were able to specify the input variables at one point in time and the output variables at a later point in time, but the processes linking one to the other remain a black box. Information about how family members perceive their choices and about the organization of community services are among the most important missing pieces to be identified.

We entered this project hoping to identify specific services which would alleviate different types of family burden. We have learned that institutionalization and use of formal services are responses to different types of caregiver burden, and that other long term outcomes are not influenced by caregiver burden, but remain responsive to levels of independence and disability of the older person. We have not, however, identified the specific service elements which will solve the problems of caregivers and frail elders. The variables in our study reflect the caregiving system, yet few government policies impact directly on that system and the variables we were measuring. An important next step is to determine which service combinations/options would meet different types of costs experienced by the caregiver. One consequence of the lack of consensus about the federal role has been to encourage a variety of approaches at state, local government, and community levels. We suggest that a basis for developing ideas for federal policy lies in the systematic evaluation of these programs. Evaluations should focus on the identification of specific models that link service programs to populations targeted by level and type of burden, as well as level of impairment of the frail person, and characteristics of the helper network. The heterogeneity in the situation of the elders suggests that no single solution may be the best.

TABLE 7-1. Summary of Multivariate Findings

	Long Term Care Outcomes, 1984			
	Nursing Home Placement	**Informal Task Support**	**Use of Formal Services**	**Hospital Admissions**
BURDEN				
Personal Burden	NO	NO	YES	NO
Interpersonal Burden	YES	NO	NO	NO
HEALTH STATUS				
ADL limitations	NO	YES	YES	NO
IADL limitations	YES	YES	YES	
Cognitive Impairments	NO		NO	
Impaired (proxy)	NO			
Chronic conditions	NO		NO	YES
SERVICE/HELPERS				
Prior Hospitalization			YES	YES
Formal helpers	YES		YES	
Informal helpers	NO		YES	
Live with others	NO			
ELDER DEMOGRAPHICS				
Sex	NO			
Race	YES		NO	
Age	YES		YES	
Per capita income			YES	
CAREGIVER DEMOGRAPHICS				
Education			NO	
Relationship	NO	NO	NO	YES

REFERENCES

Abel, E. 1987. Love is Not Enough: Family Care of the Frail Elderly. APHA Public Health Policy Series. Washington, DC: American Public Health Association.

Andersen, Ronald, and John F. Newman. 1973. "Societal and Individual Determinants of Medical Care Utilization in the United States. Milbank Memorial Fund Quarterly 51:95-124.

Arling, Greg, and William J. McAuley. 1983. The Feasibility of Public Payments for Family Caregiving. The Gerontologist, Vol 23: 300-306.

Bass, D. and Noelker, L. 1987. The Influence of Family Caregivers On Eldre's Use of In-home Service: An Expanded Conceptual Framework. Journal of Health and Social Behavior, 280:1984-196.

Birkel, Richard C. and Constance J. Jones. 1989. A Comparison of the Caregiving Networks of Dependent Elderly Individuals Who Are Lucid and Those Who Are Demented. The Gerontologist, Vol 29:114-119.

Branch, Laurence G., and Alan M. Jette. 1982. A Prospective Study of Long-Term Care Institutionalization Among the Aged. Am J. Public Health, Vol 72: 1373-1379.

Cantor, Marjorie H. 1983. Strain Among Caregivers: A Study of Experience in the United States. The Gerontologist, Vol 23: 597-604.

Cantor, M. and Little, V. 1985. Aging and Social Care. In R. Binstock and E. Shanas Handbook of Aging and the Social Sciences, (pp. 745-781). New York: Van Nostrand Reinhold.

Cohen, Marc A., Eileen J. Tell, and Stanley S. Wallack. 1986. Client-Related Risk Factors of Nursing Home Entry Among Elderly Adults. Journal of Gerontology, Vol 41: 785-792.

Colerick, Elizabeth J. and Linda K. George. 1986. Predictors of Institutionalization Among Caregivers of Patients With Alzheimer's Disease. Journal of American Geriatrics Society, 34:493-498.

Coughlin, Teresa A., and Korbin Liu. 1989. Health Care Costs of Older Persons With Cognitive Impairments. The Gerontologist, Vol 29:173-182.

Coulton, Claudia and Abbie K. Frost. 1982. Use of Social and Health Services by the Elderly. Journal of Health and Social Behavior, Vol 23: 330-339.

Day, A. 1985. Who Cares? Demographic Trends Challenge Family Care for the Elderly. Population Trends and Public Policy. 9:1-17.

Deimling, G. and S. W. Poulshock. 1985. The Transition from Family In-home Care to Institutional Care: Focus On Health and Institutional Issues As Predisposing Factors. Research on Aging, 7 (4):563-576.

Doty, P. 1986. Family Care of the Elderly: The Role of Public Policy. The Milbank Quarterly, 64:1, 34-75.

England, Suzanne E. In press. Family Leave and Gender Justice. Affilia.

Exploding the Myths: Caregiving in America. 1987. A Study by the Subcommittee on Human Services of the Select Committee on Aging, House of Representatives, 100th Congress, 1st Session. Comm. Pub. No. 99-611.

Greene, Vernon L. 1983. Substitution Between Formally and Informally Provided Care for the Impaired Elderly in the Community. Medical Care, Vol 21: 609-618.

Hamblin, R., & Hamblin, D. 1982. Category versus Magnitude Scaling and Social Surveys. Working paper, Washington: Urban Institute.

Hanley, Raymond J., Lisa Alexcih, Joshua M. Wiener, and David Kennell. 1989. Predicting Elderly Nursing Home Admission: Results from the 1982-84 National Long-Term Care Survey. Presented American Public Health Assoc., Chicago, IL, Oct. 1989.

Horowitz, A. 1985b Family Caregiving to the Frail Elderly In C. Eisdorfer (ed.). Annual Review of Gerontology and Geriatrics (pp. 194-246) Vol. 5. New York: Springer Publishing Co.

House, J., D. Umberson and K. Landis. 1988. Structures and Processes of Social Support. Annual Review of Sociology, 14.

Hughes, Susan L., Larry M, Manheim, Perry L. Edelman, and Kendon J. Conrad. 1987. Impact of Long-Term Home Care on Hospital and Nursing Home Use and Cost. Health Service Research, Vol 22: 19-47.

Hughes, Susan L., Kendon J. Conrad, Larry M. Manheim, and Perry L. Edelman. 1988. Impact of Long-Term Home Care on Mortality, Functional Status, and Unmet Needs. Health Service Research, Vol 23: 269-294.

Johnson, C. and Catalano, D. 1983. A Longitudinal Study of Family Supports to Impaired Elderly. The Gerontologist, 23: 612-618.

Joreskog, K. G. and Sorbon, D. 1986. LISREL VI; Analysis of Linear Structural Relationships by Maximum Likelihood, Instrumental Variables and Least Square Methods. Mooresville, IN: Scientific Software, Inc.

Kane, Rosalie A. 1989. The Noblest Experiment of Them All: Learning from the National Channeling Evaluation. Health Services Research, Vol 23:191-197.

Kane, Robert L., Ruth Matthias, and Susan Sampson. 1983. The Risk of Placement in a Nursing Home After Acute Hospitalization. Medical Care, Vol 21: 1055-1061.

Keeler, E.B., Kane, R. L. and Solomon, D. 1981. Short- and Long-Term Residents of Nursing Homes. Medical Care, 19:363-369.

Kessler, Ronald C. and David F. Greenberg. 1981. Linear Panel Analysis: Models of Quantitative Change. New York: Academic Press.

Kosberg, J. and R. Cairl. 1986. The Cost of Care Index: A Case Management Tool for Screening Informal Care Providers. The Gerontologist, 26:273-278.

Lang, A.M. and Brody, E., 1983. Characteristics of Middle-aged Daughters and Help to their Elderly Parents. Journal of Marriage and the Family, 45:193-202.

Litwak, Eugene. 1985. Helping the Elderly: The Complementary Roles of Informal Networks and Formal System. New York: Guilford Press.

Macken, C. 1985. A Profile of Functionally Impaired Elderly Persons Living in the Community. Health Care Financing Review 7: 51-58.

Manheim, Larry M. and Susan L. Hughes. 1986. Use of Nursing Homes by a High-Risk Long-Term Care Population. Health Service Research, Vol 21: 161-176.

Manton, Kenneth G. 1988. A Longitudinal Study of Functional Change and Mortality in the United States. The Gerontologist, 5:153-161.

Manton, K. and Liu, K. 1987. The 1982 and 1984 National Long Term Care Surveys: Their Structure and Analytic Uses. Presented at the National Conference on Long Term Care Data Bases, May 21-22. Washington, D.C. [http://aspe.hhs.gov/daltcp/reports/87cfpkes.htm]

McAuley, William J., and Greg Arling. 1984. Use of In-Home Care by Very Old People. Journal of Health and Social Behavior, Vol 25: 54-63.

McCubbin, H. and J. Patterson. 1983. The Family Stress Process: The Double ABCX Model of Adjustment and Adaptation. In. H. McCubbin, M. Sussman, & J. Patterson (eds.), Social Stress and the Family: Advances and Developments in Family Stress Theory and Research (7-37). New York: Haworth Press.

McKinlay, J. & Tennestedt, S. 1987. Social Networks and the Care of Frail Elders. Final Report, NIH/NIA Grant #AGO3869. Boston.

Mechanic, David. 1979. Correlates of Physician Utilization: Why Do Major Multivariate Studies of Physician Utilization Find Trivial Psychosocial and Organizational Effects? Journal of Health and Social Behavior, 20:387-396.

Miller, Baila, Stephanie McFall and Andrew Montgomery. 1988. The Impact of Elder Health, Caregiver Involvement, and Global Stress On Two Dimensions of Caregiver Burden. Presented at Family Care Conference, Michigan State University, March, 1989.

Montgomery, Rhonda J.V., and Edgar F. Borgatta. 1989. The Effects of Alternative Support Strategies On Family Caregiving. The Gerontologist, 29:457-464.

Mutran, Elizabeth and Kenneth F. Ferraro. 1988. Medical Need and Use of Services Among Older Men and Women. Journal of Gerontology, 43:162-170.

Noelker, Linda S. and David M. Bass. 1989. Home Care for Elderly Persons: Linkages Between Formal and Informal Caregivers. Journal of Gerontology, 44:63-70.

Osterbusch, S., Keigher, S., Miller, B. and Linsk, N. 1987. Community Care Policies and Gender Justice. International Journal of Health Services, 17: 217-231.

Paringer, L. 1983. The Forgotten Costs of Informal Long-term Care. Washington, DC: The Urban Institute.

Pfeiffer, Eric M.D. 1975. A Short Portable Mental Status Questionnaire for the Assessment of Organic Brain Deficit in Elderly Patients. American Geriatrics Society, 23:433-441.

Poulshock, S. W. & Deimling, G.T. 1984. Families Caring for Elders in Residence: Issues in the Measurement of Burden. Journal of Gerontology 39: 230-239.

Robinson, B. 1983. Validation of A Caregiver Strain Index. Journal of Gerontology, 38:344-348.

Shapiro, Evelyn, and Robert Tate. 1988. Who Is Really at Risk of Institutionalization. The Gerontologist, Vol 28: 237-245.

Soldo, Beth J. 1985. In-Home Services for the Dependent Elderly. Research on Aging, Vol 7: 281-304.

Stephens, S.A. and Christianson, J.B. 1986. Informal Care of the Elderly, Lexington, MA: Lexington Books.

Stoller, Eleanor P. and Karen L. Pugliesi. 1988. Informal Networks of Community Based Elderly. Research on Aging, Vol 10: 499-516.

Stoller, Eleanor P. and Lorna L. Earl. 1983. Help With Activities of Everyday Living: Sources of Support for the Noninstitutionalized Elderly. The Gerontologist, 23:64-70.

Stone, R., Cafferata, G., & Sangl, J. (1987). Caregivers of the Frail Elderly: A National Profile. The Gerontologist, 27, 616-626.

Tennstedt, Sharon L., John B. McKinlay, and Lisa M. Sullivan. 1989. Informal Care for Frail Elders: The Role of Secondary Caregivers. The Gerontologist, 29:677-683.

Tennstedt, Sharon, John McKinlay, Lisa Sullivan, Ralph D'Agostino. 1988. Predictors of Primary Source of Community Long-Term Care for Frail Elders Formal vs. Informal. Presented at American Public Health Association, Boston, MA.

Teresi, Jeanne, John Toner, Ruth Bennet, and David Wilder. 1988. Caregiver Burden and Long-Term Care Planning. Journal of Applied Social Sciences, Vol 13: 192-199.

Toseland, Ronald W., and Charles M. Rossiter. 1989. Group Interventions To Support Family Caregivers: A Review and Analysis. The Gerontologist, 29:438-448.

Townsend, Aloen L. 1988. Family Caregivers Perspectives on the Institutionalization Decision. Paper presented at Gerontological Society of America meeting, San Francisco.

Ungerson, Clare. 1987. Policy is Personal. London: Tavistock Press.

Wan, Thomas, T.H. 1987. Functionally Disabled Elderly: Health Status, Social Support, and Use of Health Services. Research on Aging, Vol 9: 61-77.

Wan, Thomas, T.H. and Greg Arling. 1983. Differential Use of Health Services Among Disabled Elderly. Research on Aging, Vol 5: 411-431.

Weissert, W.G. 1985. Seven Reasons Why It Is So Difficult To Make Community-based Long Term Care Cost-effective. Health Service Research, 20:423-433.

Wolinsky, Fredric D. 1978. Assessing the Effects of Predisposing, Enabling, and Illness-Morbidity Characteristics on Health Service Utilization. Journal of Health & Social Behavior, Vol 19: 384-396.

Wolinsky, Fredric D. and Rodney M. Coe. 1984. Physician and Hospital Utilization Among Noninstitutionalized Elderly Adults: An Analysis of the Health Interview Survey. Journal of Gerontology, Vol 39: 334-341.

Wolinsky, Fredric D., Rodney, M. Coe, Douglas K. Miller, John M. Prendergast, Myra J. Creel, and M. Noel Chavez. 1983. Health Services Utilization Among the Noninstitutionalized Elderly. Journal of Health & Social Behavior, Vol 24: 325-337.

Wooldridge, Judith and Jennifer Schore. 1988. The Effect of Channeling on the Use of Nursing Homes, Hospitals, and Other Medical Services. Health Services Research, Vol 23: 119-127. [http://aspe.hhs.gov/daltcp/reports/hsres.htm]

Zarit, Steven H., Karen E. Reever, and Julie Bach-Peterson. 1980. Relatives of the Impaired Elderly: Correlates of Feelings of Burden. The Gerontologist, Vol 20: 649-655.