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FACTORS AFFECTING THE PROVISION OF SOCIAL SUPPORT: A LONGITUDINAL STUDY OF FRAIL ELDERS IN TWO COMMUNITIES

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Finally, the process that began almost ten years ago is drawing to a close. I would like to take this page to thank my family and friends for their patience and forbearance as well as for their impatience and displeasure.

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Factors Affecting the Provision of Social Support: A Longitudinal Study of Frail Elders in Two Communities

Sydelle Raffe

ABSTRACT

This dissertation identifies conditions and circumstances that lead to, sustain, or diminish the provision of informal social support. The study was conducted with two samples of community-residing frail elderly who participated as treatment and control group members in a HCFA sponsored evaluation of community-based long-term care demonstration programs.

Provision of social support was operationalized as level of caregiving effort. Demographic characteristics, physical functioning, mental and emotional functioning, social resources, and receipt of formal services were evaluated for their relative contributions to provision of care. Using longitudinal data, the study analyzed deviational change in independent and dependent measures; used factor analysis to identify underlying global constructs which were unrelated to each other; and, finally, used study samples and measures which varied somewhat from each other as a replicative strategy.

Differences in factor structure, change in caregiving, and conditions relating to caregiving effort were attributed in large part to frailty level and participation in the demonstration program. Key findings include: among severely impaired elders, social contacts may become indistinguishable from caregiving contacts. After accounting for initial level of effort and program participation, the study found that socio-emotional and cognitive functioning did not account for provision of help. For most sample members, changes in physical impairment were most salient. However, severely impaired comparison group members appear to receive help without regard to their changing needs. Caregiving network extensiveness and caregiving burden followed change in need for help as salutary conditions. Burden may be a more important factor where friends and neighbors are relied upon more than family members and may only have a negative impact on caregiving at very high levels. Among the moderately impaired, case management may have functioned to help caregivers respond to changing needs, and among the severely impaired, to elicit more help from spouses even beyond what was ostensibly needed. Where impairment is moderate, programs appear to reduce informal care. But, even where impairment is severe, how community programs function can have a salutary or inhibitory effect on informal care.

Leonard I. Pearlin

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I. INTRODUCTION

The central goal of this dissertation is to identify the conditions and circumstances (social, situational, and personal) that lead to, sustain, or diminish the provision of informal social support. The study focuses on one particular group of individuals for whom the continued provision of help from informal sources is critical to their well-being -- frail elders. While the Federal government recognizes the need for public involvement in care for the frail elderly, economic considerations in the public provision of care bear heavily on policy formulation. Understanding the ability of family, friends, and neighbors to continue providing social support is particularly important for the growing population of frail elders who, but for the efforts of informal caregivers would be unable to continue living in their communities. But it is also not surprising that the interplay between formal and informal care is of particular concern to policy makers.

STUDY OBJECTIVES

The study has the following main objectives:

o To identify from the literature on social support the conditions associated with the ability to maintain and augment and the conditions which inhibit the ongoing provision of social support in the lives of the elderly.

o To conduct an examination of the interplay of formal resources and informal social support to determine if formal support enhances or limits the provision of informal support.

The study has two major features which strengthen the examination of the problem. First, the study utilizes longitudinal data which are particularly suitable to the question at hand. Observing the covariation of individual perceptions and behaviors over time is the best way to establish relationships with clarity. Second, the study uses a replicative strategy by examining the problem in two independent study samples. In essence, the study tests in one sample relationships encountered in another, increasing generalizability of findings where similarities are observed and identifying limits to generalizability where findings are not confirmed. Functional, social, demographic and contextual differences between the two study samples become important sources of limits to theoretical formulations.

PURPOSE AND SIGNIFICANCE OF THE STUDY

The goal of the research described herein is to develop and evaluate an explanatory model of social support. Such a model will furnish relevant information on which to base policy decisions regarding service provision for the older population. The issue of public versus private support of the older population is a prominent debate, with enormous economic and individual implications making the question posed in this dissertation a cynosure of public policy concern.

The provision of aid and emotional sustenance to the elderly has traditionally been, and continues to be, the province of the web of social relations in which most elderly are embedded. As is true at other life stages, these social networks are the source of social support. Whether individuals are conscious of the phenomenon or not, there is concensus that emotional and instrumental social support are necessary for well-being. What is remarkable in late life is that there is an increased need for concrete assistance. Sometimes, this need leads to a reintensification of relationships based on the provision of aid. Intermittent supportive efforts which once might have sufficed are no longer sufficient for needs which now demand response on a daily and often constant basis. On a population scale, those most in need of constant care are those over age 85, the fastest growing segment of the older population. This population growth, combined with social trends such as the movement of adult daughters into the work force and the fact that many adult children are aging themselves, introduces potential limits on the traditional sources of help.

The phenomenon of providing help to the frail elderly has been the subject of intensive study for a number of years. Early efforts documented the extent to which such help was provided, laying to rest the myth that families abandoned their elderly relatives in institutions. A very small percentage of the elderly reside in nursing homes at any one time and most elderly will never utilize a long-term care institution. Now that the often heroic efforts of families have been recognized, emphasis has shifted to developing ways to enable families to provide the kind of care required. Public sources of care are never likely to substitute for the extensive informal care provided.

In spite of the soaring health care costs born by Medicare and Medicaid, the provision of health care for older persons is not structured to provide the bulk of needed services. Though the health status of the older population as a whole has improved in recent decades, the likelihood of suffering functional decrements and chronic problems has increased, especially as the likelihood of surviving to extremely old age increases. In old age, one can ultimately expect to experience a general slowing down, loss of mobility, sensory deficits and an increased likelihood of developing diseases such as athero- and arteriosclerosis and arthritis that interfere with the ability to get around, dress, bathe and feed oneself, shop, cook and clean. Medical attention may be required, but these needs decidedly require custodial care on a daily basis over extended periods of time.

The sustained nursing and personal care needs that predominate in the older, especially in the old-old population, are not reflected in Medicare budget allocations which are oriented toward acute, episodic care in institutional (nursing home or hospital) settings. Estes (1979) estimated that less than 2% of the Medicare budget is available for services relevant to the needs of the aged in the community. While it is possible to purchase necessary services, many older individuals and their families do not have the necessary income or savings to pay for such services on an extended basis.

By and large, the needs of this population do not go unmet. Survey upon survey has found that it is the family, primarily spouses, but often adult daughters and daughters-in-law, who provide the majority of direct services to older persons. Typically, help is provided with shopping, transportation, cleaning, cooking, personal care, and companionship. However, even those who require nursing care in the community tend to have these needs met by family members (Brody, 1978). Friends and neighbors also form an important, if ancillary, part of the network of support of these older persons (Cantor, 1979).

Despite the history of care provision described above, the juxtaposition of demographic trends and rising costs of health care have prompted concern from many quarters regarding public versus family responsibility for provision of care. In part, government concerns lie with the costs of care associated with nursing home and hospital use, care modalities relied upon when there are no informal sources of care or when families can no longer provide the care required. Though relatively few frail elders avail themselves of formal services typically available in communities, community-based service programs with outreach components or which are structured to serve large segments of the older population (such as those applying to nursing homes) will become more prevalent as needs and demands for service of the older population increase and are juxtaposed with demographic, and social and economic changes which threaten to overwhelm the capacity of informal resources. Major efforts by the Health Care Financing Administration are being directed toward determining the most effective ways of providing and reimbursing for this type of care, in the hopes that the use of more expensive care modalities such as hospitals and nursing homes will be reduced. Underlying the shifts in public policy lies a major question usually cast as "the substitution debate": will providing formal services in the community in order to forestall use of institutions replace the help provided by informal sources of support? Should this replacement occur, costs of providing enough formal care to maintain community residence would become prohibitive.

Unfortunately, recent program evaluations reveal that community-based care does not necessarily produce cost savings, especially if expensive home care services replace the aid which would have been provided by the existing web of social relationships. It is clear that the informal system of care must continue to be the bulwark of service provision to frail elderly in the community.

Much of the extant literature is cross-sectional in nature and thus the longitudinal functioning of social support networks is less well documented. In addition to being primarily cross-sectional in nature, the extant work in the field has also not adequately evaluated the joint and individual effects of these factors on the provision of support. An optimal way to precisely identify the key factors and their role in providing social support is to assess the ways in which explanatory factors and social support vary together over time. Furthermore, the desirable model must analyze not only the relationship of theoretical constructs to social support, but must examine the complex interrelationship of the constructs to each other in order to understand how they work together to influence social support.

Recognizing these gaps in the literature, this dissertation uses a longitudinal design to examine factors suggested by previous studies to be related to caregiving and social support. The study evaluates their relative contributions to the provision of informal social support, analyses the phenomenon over time, and does so in samples representing somewhat different components of the frail elder population. As a secondary analysis of data collected from two samples of frail elders who were participants in HCFA funded demonstration studies of coordinated community-oriented long-term care programs, the study affords a unique opportunity to address the interplay between formal and informal sources of care in the context of the framework provided by the construct of social support.

The research is designed to pinpoint the conditions under which informal social support continues to be provided. Focusing precisely on which factors are more or less important in their effect on support enables interventions to be designed which are most likely to have the desired effect on the support network.

ORGANIZATION OF THE REPORT

The research study which follows begins with an in-depth discussion of the construct of social support, in particular social support among the frail elderly (Chapter II). Background is provided on general approaches to the study of social support and its various meanings. The social support literature is examined for factors which might explain why support is given, who is likely to give it, the types of support provided, and under what conditions support is elicited and withdrawn. The aspects of social support addressed in this study are clearly identified (e.g., provision of instrumental aid), as are those which are not (e.g., provision of emotional support). Next, the role which informal social support systems play in the lives of elderly persons, especially the frail elderly, is described and includes information on the size of these networks, their composition, the kinds of help provided, and the extent to which these sources of support help frail elders. Also informative with regard to the study questions are the demographic and population characteristics of the elderly and their potential helpers.

Chapter III describes the methods used in the study. Based on the literature reviewed in Chapter II, specific research questions and aims are presented. The community-based demonstration projects from which the study samples are drawn and the impact of the programs on the provision of informal social support are reported. The data which are available for analysis are described, and reliability and validity of the data are discussed. The analytic approach sets forth methodological issues and problems of the study and proposes an approach to minimize the effect of these issues on the analysis. Use of two samples is cast as a replication strategy. Initial descriptive findings and relationships among the study constructs are presented and discussed in Chapter IV. Chapter V builds on these findings and develops explanatory models of social support, evaluating the relevance of the models for different components of the samples. The research is summarized, conclusions drawn, and policy implications discussed in Chapter VI.

II. BACKGROUND

OVERVIEW

This chapter provides the context from which the research questions are derived. It begins with a discussion of the construct of social support followed by the role which informal social support systems play in the lives of elderly persons, especially the frail elderly. Factors purported to affect the viability of support over time are discussed in this section. Recent studies, including the evaluation of the programs whose data are used in this study, are described in relation to the role formal services play in the provision of informal support.

THE CONSTRUCT OF SOCIAL SUPPORT

In order to establish a framework for the study, three aspects of the multi-faceted construct of informal social support are described: definitions; functions; and effects on providers.

A broad definition of social support includes both affective and instrumental support (Lin, 1979; Hogue, 1976; Gottleib, 1983; Silver & Wortman, 1982; Wills, 1985).[1] Affective support includes feeling cared for and loved, esteemed and respected (Cobb, 1976), and that one matters (Pearlin, 1985). Emotional support provides feedback about one's behavior, especially problem solving behavior (Gottleib, 1983) and is thus a source of coping norms as well as of role models (Pearlin, 1985). While affective social support has been singled out for intensive study, it should be recognized that "much of it has a general presence, is beyond the level of awareness, and is embedded in the everyday transactions that take place between people in their prosaic pursuits" (Pearlin, 1985).

Informal instrumental support encompasses the direct provision of aid (for example, financial support and help with activities of daily living such as shopping and errands). Though a distinction is made between affective and instrumental support, even in situations which are ostensibly instrumental in nature, affective components exist or develop. This study, however, directly addresses only the provision of instrumental support.

Whether instrumental and/or affective, informal social support is provided by members of <u>primary social networks</u>, the social ties among individuals. Not all members of a social network will provide support; social network members are only potential providers of support. Cantor (1979) introduced the notion of "functional support", referring to those persons who are available and capable of offering meaningful support. Reference is also made in this literature to <u>support systems</u> which can be thought of as those members of social networks who actively provide support. Hogue (1976) defines a support system as "a set of persons consisting of a focal or anchor person, all the family, friends, and helping persons who stand ready to serve the anchor person, and the linkages or relationships among these people" (p.3). The degree to which these constellations of people form effective and efficient systems has not been established.

The constructs of social support and of social network are frequently studied for their ability to effect health and to buffer the effects of stress. Social support has been linked to the following benefits[2]:

- coping with undesirable events (Silver & Wortman, 1982);
- compliance with medical regimens (Cobb, 1979);
- recovery from illness (Croog, Lipson & Levine, 1972);
- more positive childbirth outcomes (Nuckolls, 1972);

- reduced mortality risks (Berkman & Syme, 1979);
- perception of general well-being (Cohen & Brody, 1981); and,
- buffering the effects of life transitions and crises (Cobb, 1976)

The mechanisms by which social support produce these salutary effects are both direct and indirect, and include: reinforcing self-esteem; providing feedback which clarifies situations; acting as linkages to expert help; directly modifying a stressful environment; transmitting coping norms and providing role models; and, providing concrete services and tangible aid.

Like many other social phenomena, the source, nature and function of informal social support is related to life stage (Pearlin, 1985). Life stage also affects the factors which Gottlieb (1983) suggests are related to the provision of adequate instrumental and emotional aid:

- structural properties of the network as a whole, e.g., the size, density and composition affect the quality, diversity, and reliability of support;
- norms of helping which are related to ethnic and social class networks and within networks, which types of people should provide various types of aid; and
- qualitative aspects of the relationship such as the degree of intimacy.

In old age, one's social ties diminish as spouses and friends die or become less available and as children become more involved with their own children or in other roles. Norms of filial responsibility and filial behavior do vary by social class and by ethnicity, but in general, helping is gender specific, falling first to wives and then to daughters and daughters-in-law.

Cantor (1985) describes the social support needs of older people as follows:

> "Although purely medical or medically related services are sometimes involved, in general the supports are social and health related in nature and are needed to help an older person maintain physical, psychological, and social integrity over time. Thus, a social support system provides assis-

tance to older people by fulfilling three major needs:

- socialization and personal development;
- the carrying out of daily living tasks such as shopping, cleaning and laundry; and
- personal assistance during times of crisis and illness."

More recently, attention has turned to the consequences of support for the relationship of those involved (Pearlin, 1985), for those who provide support as well as for those who receive it. Whatever motives underlie helping efforts (e.g., past, current or future reciprocity, altruism, being a role model for others), providers of support may feel worthwhile and needed. They may even anchor their identity in the helping role. On the other hand, providers of support can become overburdened to the point of experiencing negative physical and emotional effects which in turn can affect their ability to continue providing help. The growing literature on burden experienced by caregivers to the frail elderly is an example of the negative effects of providing informal support. This and other aspects of social support specific to the elderly are described below.

THE ROLE OF INFORMAL SUPPORT IN THE LIVES OF THE ELDERLY

Extensive documentation now exists that informal helpers are the predominant source of assistance for impaired adults and a principal factor enabling their continued community residence (Palmore, 1976; Johnson & Catalano, 1981). Practitioners have long recognized that the use of nursing homes was a "relative" matter, influenced by the presence of a spouse in the elder's home or the availability of other family members to provide care. The importance of informal caregiving in this regard is suggested by findings that single persons living alone are much more likely to be institutionalized than those living with others

(Caplow, Bohr, Kart, Manard & Van Gils, 1974; Davis & Gibbon, 1971; Dunlop, 1979). The possibility that this finding is accounted for by health factors is countermanded by surveys which have found large numbers of elderly living in the community with levels of health impairment comparable to nursing home residents (Brody, Poulschock & Masciocchi, 1979; Dunlop, 1976). Thus, while functional abilities are related to institutional placement, the principal difference between community and nursing home populations is the presence of social resources. The following section describes the structure, composition and size of these social networks and the types of help they provide.

Structure and Composition of Support Networks

It is now well known that the principal and often exclusive source of informal assistance to the elderly is the family, though friends, neighbors and voluntary organizations play supplemental roles. Survey-based estimates of the populations of disabled older people assisted by their families range from 60% to 80% (Callahan, Diamond, Giele & Morris, 1980; Shanas, Townsend, Wedderburn, Friis, Milhoj & Stehowuer, 1968; U.S. Senate, 1982). For the majority of elderly, spouses, children and children-in-law play the central role (Frankfather, Smith & Caro, 1981; Shanas, 1979; Masciocchi, Thomas & Moeller, in press). A National Center for Health Statistics (NCHS) analysis of Health Interview Survey data for the years 1966-68 found 62% of in-home medically related and personal care to be provided by family members. Had assistance in instrumental activities been included, the percentage of needs being met would have been even higher (NCHS, 1972). The extent of help is not surprising, given that the family is the normative unit for assisting ill members, and voluntary choices for assistance (especially personal care) are based upon relationships where intimacy and trust exist. That is, as Pearlin and Johnson (1977) point out, to a great extent, the provision of support occurs in the context of ongoing primary social relationships.

These informal systems are constructed and function in a hierarchical manner. That is, those who function as primary helpers either provide the most help, are the first caregiver preferred, or bear the most responsibility for the older person. Others in the system are secondary to these primary helpers, contributing and compensating when primary helpers are unavailable. Caregiving tends to be delegated and organized according to the primacy of the relationship rather than by the nature of the tasks which need to be done. Thus, as each system becomes limited or unavailable, the next circle of the hierarchy is sought or provides care.

The primary system is usually comprised of household members, most often a spouse. When spouses are not present or are not functional, children tend to become primary sources of care; when spouses and children are not available, distant relatives become primary sources of care with friends and neighbors assuming concomitantly greater importance. The hierarchical position of support system members is determined by factors such as living arrangements, marital status, and physical proximity. These are discussed below.

For the disabled elder who is married, a spouse (when they are capable of helping) is the major and often exclusive source of assistance (Johnson, 1979; 1980; 1981). Census data from 1980 indicate that more than two-thirds of males over age 65 lived with their wives, who presumably would be their caregivers if these men were disabled. For older females, the picture is somewhat different. Older females are much more likely to be widowed and thus much less likely to have a spouse as their primary source of aid.

Children of married elders, when present, are usually the first to supplement a spouse's care. When the spouse is the principal caregiver, children's contributions take the form of instrumental assistance and respite from the well parent's responsibility (Fengler & Goodrich, 1976). When children are not available or not able to help, tertiary individuals become replacements (Cantor, 1980; Johnson, 1979; Shanas, 1979), although their willingness to assume long-term responsibilities for daily personal and instrumental care is debated. This tertiary subsystem of married elders consists of siblings and distant relatives (nieces/nephews, grandchildren) and close friends and neighbors.

The systems of single elders living alone are structured somewhat differently. These individuals rely first upon their children, when present, and upon other relatives, friends and neighbors secondarily.

To the extent that children are absent or unavailable, there is general agreement that other relatives are the primary source of assistance. In some cases, siblings and distant kin may assume major roles. Their normative role in support systems, especially those where at least one child exists, is assistance for discrete tasks with intermittent schedules. The relative prevalence of siblings and other relatives as primary caregivers is consistent across several studies (Cantor, 1980, 1977; Morris, Sherwood & Gutkin, 1982). The importance of their assistance in the typical network is greater when children are absent or unavailable (Cantor & Johnson, 1978; Stoller & Earl, 1983).

Caregiving by children, whether they be primary or secondary helpers, is a sex role-related phenomenon. Every study of social supports has documented that daughters (and daughters-in-law) are the most prevalent non-household sources of assistance (Shanas et al., 1968; Sussman, 1965; Brody, 1979; Tobin & Kulys, 1980; Lowenthal, Thurnher, Chiriboga & Associates, 1975). In part, the prominant role of women is due to the stronger emotional ties that daughters have to their parents and in part because caregiving has been a traditional female role within families.

Size of Support Systems

The size of informal support networks is another factor which has implications for the functioning of the systems and for the caregivers as well. Many older persons are embedded in large social networks and thus have multiple potential helpers. However, most active or activated informal support systems are relatively small. In studies addressing the size of informal care systems, systems consisting of one caregiver (Stoller & Earl, 1983; York & Caslyn, 1977) or two (Frankfather et al., 1981), are the most prevalent type. The study of informal support conducted as part of a national evaluation of coordinated community-oriented long-term care demonstration projects (BPA, 1985) found that very few respondents reported as many as three informal caregivers. It is possible that reporting bias is operating so that respondents are identifying fewer helpers than actually participate. If this is so, the bias appears to be a consistent one given the consistency of the findings reported.

The small size of most informal helping systems is due to a number of factors. First, the hierarchical structure of informal systems means that some helpers are preferred to others. Second, the more active the primary and secondary system are, the less active others need to be. In part, the degree to which a support person helps is related to the relationship between the helper and the older recipient. Johnson and Catalano (1981) found that when spouses were the primary caregivers, they tended to provide comprehensive help and excluded other sources. On the other hand, when children are primary caregivers, they are more likely to seek out other sources of help and share the responsibilities. Third, the size of informal networks has been found to depend in part on level of disability (Branch & Jette, 1983). In turn, level of disability is related to the living arrangements of caregivers and frail elders. Though most older persons live in their own households, as noted earlier, those who are severely impaired are much more likely to be living with others in large part because care is required on a continuing and daily basis. Thus, the greater the needs of the older person, the larger the informal support system tends to be, the more tasks supports help with, and the more likely it is that the older person will be living with someone who provides care. Finally, the small size of active support systems is also likely to be due to the logistics of providing care. Someone must know all the details, and if others are going to help, someone must coordinate their efforts. The presence of numerous helpers to be coordinated can become its own source of stress; it's often easier for the primary helper to "do it myself".

Thus, caregiving appears to be shared among a small number of active helpers, and most responsibility lies with one, or at the most, two sources of support. Primary helpers are key figures; they are not replaceable by three or four others. A large social network may mean that should one or more active helpers be unable to continue, others will be there to take their place. This backup may provide comforting reassurance to the primary caregivers as well as respite when needed. The relationship between caregiving and disability level suggests that networks do serve as latent support systems which are activated as they are needed.

Types and Amount of Informal Support Assistance

Less information about the content and amount of informal assistance is available than information on the composition of informal networks. There is wide variation in how tasks are distributed among caregivers and in the magnitude of assistance which is documented in existing studies. To some extent, position in the support hierarchy affects the types of help which are given, in that anyone with primary responsibility is often helping on a continuous basis and is likely to be helping with personal care tasks. Helpers further down in the hierarchy are more likely to be providing intermittent help, and in other than personal care areas. In the case of children who help, the involvement of sons is typically limited to the areas of financial management, mediation/linkage with formal organizations, shopping/errands and transportation (Horowitz & Dobrof, 1982; Stoller & Earl, 1983). Daughters are more likely to perform a wider range of tasks. However, the variation may also be accounted for by inadequacies and differences in research design and the lack of control for factors affecting informal network structure and function, factors such as socioeconomic status, ethnicity, urban-rural location, and the nature of impairments experienced by the older recipient. Thus, findings from this body of literature must be considered as tentative.

The tasks for which assistance is provided appear to cluster into four major groups: 1) home maintenance; 2) instrumental activities of daily living (IADL), such as shopping and meal preparation; 3) activities of daily living (ADL), such as bathing and toileting; and, 4) mediation or linkage. To a degree, the four groups of tasks are hierarchical with respect to the onset of dependencies in old age, but they are not so ordered with respect to the initiation or frequency of caregiving activities. That is, older persons may first lose the ability to perform home maintenance activities such as gardening, painting, and heavy cleaning, but these are not the most common tasks with which informal helpers provide assistance. Conversely, personal care abilities may be the most likely to be retained, yet are among the more common of tasks with which help is received.

The few studies which investigated help with home maintenance activities reported fairly low frequencies of assistance. With these types of tasks, it is possible to forego assistance when help is unavailable. Those elders who have deficits with instrumental activities of daily living tend to have mobility deficits and may be homebound. IADL assistance is the most common form of assistance provided by non-household caregivers to elders who are mildly to moderately impaired and who live alone or with a spouse who is unable to provide care.

The likelihood of recording a great deal of personal care assistance is related to the level of impairment. As noted previously, elders living alone do use less ADL assistance than those living with others (Branch & Jette, 1983), in large measure because those with high levels of personal care needs can no longer live alone. The activity most frequently provided by non-household caregivers is bathing.

The mediation or linkage activity includes interacting with formal institutions, usually health care and social service providers and welfare agencies (Sussman, 1977; Streib, 1977) on behalf of the elder. Other tasks are management/arrangement for services, problem-solving, legal and protective decision-making, financial management and other actions which ensure the aged person's well being. While few studies have inquired about this activity, indications are that it is one of the most prevalent forms of assistance provided by sons and daughters. Children with higher incomes seem to spend greater proportions of their caregiving time in these activities compared to other income groups who are more likely to provide direct services (Archbold, 1982; Cantor, 1985).

These findings suggest that activating a caregiving network is not done lightly. Elders may forego performing certain activities which are not essential to their health and well-being. For those who can afford paid help, it is not uncommon to institute or continue patterns of housekeeping help or help with tasks such as laundry or shopping. However, when the tasks with which help is required become more personal, especially those related to care of the body, it seems that a closer bond to a helper is required or at least strongly preferred, at least by the care recipient.

These studies are limited in the amount of information they relay on the extent of caregiving assistance. Studies lack comparable measures of key constructs, when measured at all, which affect caregiving such as household composition, caregiver proximity, informal network composition, and categories of assistance provided. They also lack comparable and adequate measures of the amount or extent of caregiving. Common measures of social support are caregiver presence versus absence, number of helpers, and number of tasks in which help is provided.

Few studies have addressed the frequency and duration of helping efforts.

Studies reporting correlates of caregiving help strongly suggest that however measured, the type and amount of help is related less to the nature and extent of disability and more to social and demographic factors such as relationship of the helper, visiting patterns (Croog et al., 1972), sex of the recipient (Branch & Jette, 1983; Tennestedt, 1984; Johnson & Catalano, 1981), and social class (Archbold, 1982; Cantor, 1985). That is, studies have found that among individuals with similar levels of disability, these types of factors are related to the amount of care provided by informal caregivers. It is not that disability level does not play an important role in determining receipt of home care services, but disability in itself is not a sufficient explanatory factor. The relative importance of social and situational factors to disability is also revealed in research on factors determining institutionalization. In the case of institutionalization, it is the existence of a social support system which plays a preeminent role.

FACTORS AFFECTING INFORMAL SUPPORT FUNCTIONING OVER TIME

Thus far, the long-term behavior of informal support systems has received scant attention. Given the chronic needs of the population and the evidence that institutional sources of care are uncommonly used, it is apparent that informal support to frail elders is provided over long periods of time. When asked, helpers anticipate being able to continue caring. In retrospect, helpers reported helping for longer than they expected and doing more than they expected (Morris et al., 1982). At some time in the caregiving cycle, caregivers may reduce the amount of services provided. It is only at a crisis or breaking point that informal care providers actually cease providing services. In either event, qualitative changes in the relationship may occur over the course of caregiving (see Raffe, 1982). The following factors are discussed as they relate to the longitudinal behavior of informal support systems: characteristics of support systems and assistance, delegation of tasks, characteristics of the recipient, caregiver burden, and the availability and provision of formal services.

Characteristics of Support Systems and Assistance

The effect of size on caregiving viability is fairly clear: The concensus among researchers and clinicians is that single primary caregiver arrangements, the most prevalent type, (Horowitz & Dobrof, 1982) are the most unstable and most vulnerable to collapse. Any system with one primary caregiver (whether it is a child living in another household or a spouse) is less stable because one individual bears the entire burden of assistance. While one person is usually identified as the primary caregiver, more secondary and potential caregivers widen the base over which tasks may be distributed, lowering the probability for a disproportionate share accruing to any one individual. Egalitarian sharing of caregiving tasks does not always occur and may not be feasible, but the knowledge that someone else can be called on likely contributes to the long-term stability of these systems. Thus, systems containing more individuals exhibit greater stability over time because of the shared workload and burden and are considered more likely to be able to sustain frail elders in the community.

Caregiving viability is also governed by competing demands of caregivers, often role-related but sometimes physical. As previously discussed, the most exacting caregiving roles and tasks are customarily delegated to female children (Brody et al., 1979; Blenkner, 1965; Lang & Brody, 1983), and adult daughters and daughters-in-law have traditionally been available to serve in the caregiving role. However, middle-aged and older women have increasingly entered the work force and are less available for this role. This generation of women have been characterized as "women in the middle" due to their competing responsibilities to both younger and older kin, to spouses, and increasingly to their jobs (Brody, 1980). In addition, spouses, siblings and adult children who are themselves aging may have limitations related to their own health status. Not only may they be incapable of providing complete assistance, they may require some support themselves.

It is more difficult to sustain helping efforts with some tasks, such as bathing, feeding and daily monitoring, than with others such as shopping, errands, transportation, and financial management. Paradoxically, the tasks which are more difficult to sustain help with, either because they are physically demanding or require constant attention, are precisely the tasks which must be done and which may be difficult to share with others or entrust to non-intimates. Instrumental, as contrasted with personal care activities, may be less time consuming, require intermittent rather than continual responses, and fit with the caregivers own responsibilties and lifestyle.

By implication, the greater the disability and needs of the recipient, the more difficult it may be to sustain helping efforts. Thus, while increased needs may initially elicit outpourings of support, as needs reach high levels and care must be sustained, informally provided help may no longer suffice. There is some evidence that mental impairments may be more difficult to deal with than physical impairments (Cath, 1972; Savitsky & Sharkey, 1973) and that care-recipients with attractive personalities may be easier to care for for longer periods of time (Morris et al., 1982).

While all these factors contribute to the family member's ability to continue in the caregiving role, the viability of informal support system ultimately rests on the ability of the primary caregiver(s) to accommodate the demands imposed by the disabled elder's needs without dysfunctional consequences.[3] This accommodation includes the ability to cope with the physical and psychological stresses encountered, as well as the ability to mobilize additional sources of aid when needed.

Caregiver Burden

Burden is objectively defined as the level of effort required by caregiving, e.g., the frequency and duration with which help is given. However, most evidence supports the view that burden subjectively defined is not directly related to the level of effort required (Cantor, 1981; Caro & Blank, 1984; Deimling & Bass, 1984). That is, there are a plethora of less tangible aspects of caregiving and conditions under which caregiving is experienced as burdensome and stressful. Measures of subjectively experienced burden (for example, impact on life, conflict, self-reported difficulties, stress and strain) are even more varied than measures of the frequency and duration of support. Despite these variations, the literature has yielded some generalizations about the prevalence of burden and about factors which are related to burden.

Gerontologists argue that the most problematic impact of caregiving lies in the psychological cost and stress manifestations of caregiving. Caregiving has even been observed to be inherently stressful.[4] Psychological costs, strain or stress for the caregiver and the caregiver's family (Cantor, 1980; Fengler & Goodrich, 1976; Archbold, 1978; Horowitz & Dobrof, 1982) as well as physical illness (Almind, Freer, Gray & Warshaw, 1983) are the result of continual physical demands, time which is lost, financial requirements, the disruption to other life activities, and the loss of freedom and mobility and opportunity to lead an autonomous life because of the care recipients's needs. These various impediments vary based on age and relationship of the caregiver to the recipient (Johnson, 1979).

It is unclear whether different types of caregivers, e.g., spouses and children, are more or less likely to experience stress. On the one hand, Johnson & Catalano (1981) report that distant helpers appeared to be under more strain as well as more ambivalent about helping than were spouses. Others report that spouses are more likely to experience high levels of stress (Brody, 1982; Horowitz & Shindelman, 1980). The likelihood of a primary helper experiencing high levels of stress may depend on whether or not the recipient is living with the elder (Caro & Blank, 1984; Zweibel, 1980; Horowitz & Shindelman, 1980).

The most taxing demands include physical and nursing care, excessive requests for companionship, social isolation, restrictions on employment, and social/leisure limitations (Grad deAlarcon, Sainsbury & Costain, 1975; Brody, 1979; Zarit, 1980). In addition, care recipients with emotional problems or disturbing behavior are often mentioned as more disruptive and stressful to caregivers than those with physical symptoms (York & Caslyn, 1977; Robinson & Thurnher, 1979; Cantor, 1983; Deimling & Bass, 1984).

Though the evidence is not extensive, it appears that receiving social and emotional support from others, but not necessarily receiving help with the tasks of caregiving, mitigates the amount of stress and burden perceived by caregivers (Horowitz & Shindelman, 1980; Zarit et al., 1980). As noted previously, attempting to coordinate and organize a cadre of helpers may in itself be a source of stress.

While there are no doubt many instances in which caregiving is a fulfilling and gratifying role, caregiving is most often addressed as a source of stress and burden which affects the ability to sustain the effort. There is consensus that high levels of burden are prevalent among primary caregivers, those assuming major responsibility, (Johnson, 1983) and that burden is a major factor in the deterioration of informal system functioning (Almind et al., 1983; Kutzka, 1980). Burden derives in part but not totally from the extent or intensity of caregiving. When the burden which is experienced cannot be relieved by other members of the informal support network, or because formal services are unavailable, inadequate or unaffordable (Tobin & Kulys, 1980; Weiler & Rathbone-McCuan, 1978), families turn to nursing homes. The linkage between burden, informal system breakdown, and nursing home placement has been established in research (Masciocchi et al., in press; Grad de Alarcon et al., 1975) and practice.

Formal Service Provision

The relationship between care provided by organizations (formal support) and the care provided by informal sources of support is increasingly being subjected to examination. On the one hand, informal sources of care are said to serve as linkages and referral agents to formal sources of care (Sussman, 1977); on the other hand, informal sources of help are proposed to mitigate the need for formal care and to even block its provision (O'Brien & Wagner, 1980). Two related types of information are relevant. First, the literature describes factors which appear to be related to the likelihood that older people or their informal helpers will utilize formal services. Second, studies examine the response of informal helpers to the initiation of formal services.

The overall prevalence of formal service utilization among the elderly is low. Though not necessarily studied directly, many studies of care providers, or caregiving situations have reported limited utilization of formal services (Robinson & Thurnher, 1979; BPA, 1985). At least until recently (see Brody, Davis, Fulcomer & Johnson, 1979), attitudes have favored the use of informal help even if money were not an issue (Stoller & Earl, 1983). For many elderly, using paid help lies outside acceptable social norms of helping behavior which should come from family and friends. Some elderly and their families exhibit a strong resistance to help from strangers at all.

Formal sources of help are more likely to be used by some elderly and their helpers than others. Utilization is highest among those elderly who do not have other sources of help, usually those who are unmarried and have no children (Cicerelli, 1979; Gubrium, 1975; Kivett & Learner, 1980; Ward, 1979). Caregiving children are more likely to supplement their care with formal services than are caregiving spouses. Caregiving spouses in childless marriages are probably least likely to use formal services (Johnson & Catalano, 1981).

To a great extent, research on informal helpers' response to the initiation of formal services is driven by economic considerations. That is, despite the documented tenacity of informal caregivers, there is concern that expanded home care services would undermine traditional family responsibilities and become a disincentive to informal care, that older persons would replace informal services with formal services, and that elders would unnecessarily enlarge the scope of their needs (Doty, 1984). On the other hand, formal service provision may diminish the burden of caregiving and improve informal system viability. To the extent that burden is reduced and to the extent that informal sources of care are able to sustain their efforts for longer periods of time, substitution of formal for informal services can be a desirable outcome. A distinction is thus made between "supplanting" (undesirable replacement) and "supplementing" (desirable replacement) informal care (HCFA, 1981)[5]. Explication of the dynamic interplay between formal and informal support is a central issue of this dissertation.

Empirical investigation of the response to initiation of formal service provision among frail elderly populations has been limited. Many of the studies are cross-sectional in design or use retrospective data. The studies also use a variety of measures of informal support which makes generalizations difficult.

It appears that most informal helpers think that, provided with formal services, they would not reduce their level of effort. The informal caregivers interviewed by Morris et al (1982) reported that they would maintain or increase their level of effort even if formal services were provided. Only 5.6% said they would reduce their contact with the impaired elder. In one cross-sectional investigation of 500 impaired elderly, a judgment of "no replacement" was based upon the finding that the number of informal caregivers would not be significantly reduced by the provision of formal home care services (Morris et al., 1982). Other cross-sectional studies of the level of caregiving effort however, find some evidence of replacement. Analysis of retrospective data on 124 clients of a case management/homecare agency found that when formal services in one additional task were introduced, caregivers responded to the increase in formal services by reducing the number of tasks with which they provided help.

California's Multipurpose Senior Services Project (MSSP) took a similar approach in analyzing initial assessment data from 1884 experimental group members and 1044 control group members. The cross-sectional analysis (the only results available at this time) were implemented in each group separately. The treatment group was somewhat more impaired than the control group; both groups were eligible for Medicaid and thus represent low income frail elders. Regression analyses were used to estimate the effects of "factors which promote or discourage provision of informal support" on a measure of informal support. The measure of informal support was the number of tasks (covering 19 activities) with which respondents reported receiving sufficient help. Factors proposed to promote or discourage support were the respondent's need for help in performing the 19 tasks, receipt of formal services (hours per week in six task categories), and family characteristics or living arrangements. Bivariate analysis found that need was strongly related to informal caregiving; receipt of formal services was related to informal caregiving only for the less frail control group. Because the authors found that the strongest determinant of informal services was whether or not the individual lived alone, analysis proceeded to examine four groups: clients living alone, clients living with others, controls living alone, and controls living with others. Within these subgroups, Smith, Talbott, & Miller (1982) attempt to discern the effects of nine different types of potential supports (e.g., a son close by, a daughter close by, and so forth). By including interaction effects between each family type and need for help as well as receipt of formal services, the analysis attempts to assess the differential effects of different family types across all levels of formal service receipt. Findings from the extensive discrete analyses are difficult to synthesize. For the purposes of the present study, it is sufficient to point out that the observed relationships between formal service use and informal care were mediated by living arrangements and by the composition of the family network. In some instances, more formal help was associated with less informal care (e.g., among clients living with others, spouses gave less formal care in the presence of formal services) and in other instances, more formal help was associated with more formal care (e.g., among controls living alone, sons and nearby daughters gave more informal care in the presence of formal services). For the more frail clients, it appears that more intimate family members (spouse and children) are more powerful mediators of relationships whereas among the less impaired control group, whether living alone or with others, the presence of a wider range of family and friends (nonrelatives, siblings, grandchildren) mediate the relationship between formal services and informal care.

The above studies are limited in that they did not observe changes over time in caregiving. Relying on data collected at a single point in time, it is difficult to assess effects of independent on dependent variables. Both formal and informal caregivers are simultaneously responding to client needs and more impaired individuals are likely to receive more help from all sources. Longitudinal data provides an improved forum for detecting causal relationships among factors. Two major studies using longitudinal data are described, the National Evaluation of Coordinated Community-Oriented Long-Term Care demonstration projects (BPA, 1985) and Channeling Effects on Informal Care (Christianson, 1986).

The demonstration projects evaluated by BPA implemented a test of the effects of the provision of case-managed long-term care services on informal support over a one year period in three project sites. The question was addressed by evaluating treatment/comparative group differences after a one-year period on outcome measures of residual formal service need in: Activities of Daily Living (bathing, dressing, feeding, toileting, and transfer) and Instrumental Activities of Daily Living (meal preparation, shopping, transportation, medication administration, finances, and housekeeping). These measures incorporated functional need as well as source of support, formal and/or informal. In combination with measures of change in level of effort (frequency or amount of help), the report concluded that undesired replacement had taken place in two of the three projects studied (New York City and San Diego); in those two projects, informal service use diminished with the use of formal services. In the third project (South Carolina), treatment group members utilized more formal services without the level of informal help being affected. However, upon close examination of the tables provided in the report, it appears that the analysis results for the New York City project were interpreted in the wrong direction. Rather than decreasing, assistance in personal care tasks increased. For less impaired clients, help in instrumental tasks decreased while for more impaired clients no effect on instrumental help was observed. Thus, of the three projects, the New York City project appears to have had mixed impacts with a positive overtone (more as well as less informal help), the South Carolina project a positive impact (in that informal care in ADL and IADL was maintained), and the San Diego project a mixed impact with negative overtones (maintained or decreased informal help).

The report suggested factors which are still relevant for explaining the differences among the projects despite the reinterpretation of some of the study findings. The first is the model of case management and how it was put into practice and the second is the nature of the populations served by the projects. The report points out that in South Carolina, the case management process emphasized the use of informal helpers prior to providing formal services. Apparently, the New York City program was also successful in this regard. Though all the projects had guidelines directing workers to consider the informal system first, these projects appear to have been successful at putting policy into practice. The report points out that the South Carolina program was a nursing home pre-admission screening program which served a population at high risk of institutionalization. The New York City project served a population almost as impaired, but the participants were not nursing home bound. San Diego served a less impaired population.

The Channeling demonstrations were also sponsored by HCFA and began operations in 1980 in 10 sites around the country. These demonstrations shared a common goal with the Community-Oriented demonstrations described above. Both initiatives aimed to maintain frail elders in their communities and out of nursing homes for as long as feasible and to reduce other forms of institutional care (hospitalization) without spending more public funds than would have been spent in the absence of the programs. The Channeling demonstration tested two models of service provision: the basic case management model, in which case managers directed clients to and monitored available community services; and the financial control model which provided a set of expanded services and used a cap on total services to control costs. Effects of the programs were assessed on an array of measures of informal support including the number of different services provided, the proportion of sample members with an informal caregiver, and the number of hours of care received. Using client assessment data, under the basic model (no expanded services), no evidence of substitution was found. In the financial control model which offered some expanded services, a modest degree of substitution was observed for certain services. No evidence of reduction in informal care from the primary caregiver was observed, only among secondary members of the helping network. No effect was observed on the number of hours of informal care received. The report concludes that caregivers shifted their efforts to other arenas, especially to making arrangements for services. A study of primary caregiver data found short-term (within 6 months) positive effects on some aspects of primary caregiver well-being, but found no evidence of reduced self-reported strain associated with caregiving.

For the most part, none of these studies attempted to explain their findings since they were interested in the effect of only one variable, the demonstration program, on the provision of informal support. Any factors (such as level of impairment or living arrangement) which could obfuscate the relationship between the program and informal support outcomes were statistically controlled. Data available from the BPA evaluation thus provides a fertile field for an explanatory study.

SUMMARY

A framework for the present study is provided by the complex construct of social support. It was noted that the study of social support, in general, has focused on its relationship to health and other outcomes of importance. Fewer efforts have been directed toward explaining the provision of social support itself. Extensive evidence was presented demonstrating that the form of social support to frail elders which entails provision of direct services is extensive, enduring, and related to a complex interplay of health and social factors. Important factors related to the rendering of aid and to the continued provision of social support include: demographic characteristics (e.g., sex and marital status of recipient); physical functioning and impairment (e.g., ability to perform activities of daily living); mental and psychological functioning (e.g., mental status and behavior problems); social resources (e.g., size and composition of the social network); caregiver burden; and formal service provision. Extant work in the field has not adequately evaluated the joint and individual effects of these factors on the provision of support in a model which would explain the maintenance, increase or decrease of support.

The next chapter describes how the study addresses the questions posed.

NOTES

[1] In fact, Cobb (1976) excludes the activities of goods and services from the definition of social support, stating that the former may foster dependency while the latter, by definition, encourages independent behavior.

[2] Some researchers have addressed the potential negative effects of

social relations ostensibly identified as social support, for example, families who interfere with rehabilitative efforts. But, for the most part, the quality of help the has been unexamined within the framework of social support. In part, this is probably due to the nature of the construct: any behavior which had a deleterious effect on an outcome would not be defined as social support.

[3] Johnson and Catalano (1981) describe two mechanisms used by caregivers to cope: enmeshing in the role and emotionally distancing oneself.

[4] Caregiving has also been observed to have its rewards for those who provide support to others (Johnson & Catalano, 1981).

[5] The research to date has ignored the controversial question of the quality of informal help. Lee (1985) raises the issue pointing out that, in reality, older persons and their families do not have a choice regarding sources of help due to the costs involved. He notes that examination of informal help must go beyond the substitution or replacement debate to a study of the adequacy of informal help for older persons.

III. METHODS

In order to address the purposes of this study, major research questions and research aims are posed in this chapter. Next, a section on data sources and data quality describes the study samples and variables used for this secondary analysis and discusses the strengths and limitations of the data sets. Finally, the analytic approach required for purposes of explanation is described.

RESEARCH QUESTIONS AND AIMS

In examining the provision of informal support to frail elderly residing in the community, the overriding question to be addressed is: "What are the relative contributions of different factors and conditions to explaining change and stability in informal support?" The emphasis of this study is on formulating and testing an explanatory model with secondary data in order to understand how and why informal caregiving comes about, is sustained, and diminishes. The study is less concerned with the ability to predict or account for change or stability in caregiving.

The material presented in the previous chapter suggested a set of interrelated factors and conditions likely to be related to changes in informal caregiving. These factors include:

- Frail elder demographic characteristics such as sex, marital status, living arrangements, and income;
- Frail elder physical and mental functioning;
- Caregiver characteristics such as relationship to the elder and types of assistance provided;
- Social network involvement of the frail elder;
- Composition and size of the informal support network;
- Burden - limitations of the caregiver; and,
- Receipt of formal services.

I assume that changes in factors and conditions will result in changes in the provision of care. Thus, it is covariation of these factors with informal care over time that will enable the connection between conditions and informal care to be explicated and to identify those that are most influential to caregiving.

Factors extracted from the literature, such as marital status and sex of the frail elder, will be used to test the generalizability of observed relationships. It may be the case that a single set of explanatory factors will not apply to a general population of frail elders and their caregivers. The research thus addresses findings which suggest that the force of social roles may be more important in determining caregiving involvement than actual need for care on the part of frail elders. Therefore, once a model based on selected factors is established, the study investigates for whom and under what situations the factors in the model are viable.

Previous research does not give a clear indication of which factors are relatively more important when considered together. While physical functional disability has been found to be significantly related to caregiving, it's importance in the presence of cognitive impairment is unclear.

The following section describes the samples and variables used in this study.

DATA SOURCES AND DATA QUALITY

The National Evaluation of Community-Oriented Long-Term Care Projects

This study is a secondary analysis of data collected for a national evaluation of community-oriented long-term care programs conducted by Berkeley Planning Associates (BPA) (see BPA, 1985).[1] To explore different approaches to providing and financing publicly-supported community-based long-term care, the Health Care Financing Administration (HCFA) in late 1980 sponsored a national evaluation of 13 projects demonstrating the provision of coordinated, community-oriented services to impaired and aged Medicare and Medicaid beneficiaries.2 These projects provided long-term care under Section 222 Medicare and/or Section 1115 Medicaid waivers that allowed reimbursement for clients and for services not typically covered by Medicare and Medicaid. Each project used a quasi-experimental study design with a treatment group, those who received the special demonstration services, and a comparison group which continued to be served in the traditional system of care. Each group was followed and assessed periodically for at least one year. The treatment and comparison (or control) groups were used to assess the impact of the service program on participant health and well-being and on service utilization and costs. The treatment intervention typically consisted of some type of case management and some set of expanded Medicare or Medicaid home care services. Comparison or control group members utilized the traditional system of care. The 13 projects varied in a number ways, including the types of expanded services offered, organizational aegis, organizational structure, type of case management, and the populations of older persons targeted to receive services.

In addition to studying the effects of the projects on physical and mental status, and on utilization and costs of health care services, three of the projects (the Long-Term Care Demonstration Project of North San Diego County [a Medicare demonstration], the New York City Home Care Project [a Medicare demonstration], and the South Carolina Community Long-Term Care Project [a Medicaid demonstration]) were also used in the national evaluation to test the impact of the interventions on provision of informal help. The question addressed in that evaluation was: "Did participation in the project supplement or supplant informal support services relative to comparison group members?" The question was addressed by evaluating treatment/comparison group changes over a one year period on two sets of outcome measures: 1) unmet Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) needs (defined as the residual formal service need observed after informal system participation is accounted for); and 2) magnitude of informal assistance received (number of assistance episodes or days of care per week for the ADL and IADL tasks).

The projects' evaluation was concerned with the effect of only one variable on informal caregiving: treatment-comparison group membership.[3] By and large, the evaluation did not ask <u>why</u> caregiving did change, aside from participation in the program. The findings of these analyses are briefly described below.

Program impact was assessed using analysis of covariance with the baseline measure of informal caregiving and any treatment-comparison group differences used as covariates and group membership as the factor. Conventional significance levels ($p \leq .05$) were used to identify findings which were reasonably unlikely to have arisen by chance.[4] In each of the three projects, treatment group members were found to be receiving <u>more formal services</u> after one year relative to their respective comparison groups. An increase in formal services was not surprising given that special waiver services were part of the intervention. However, in South Carolina, treatment clients were found to be receiving <u>the same amount of help</u> from their informal caregivers relative to comparison group members at the end of one year in both ADL and IADL tasks. In San Diego, while treatment group clients were receiving the same amount of ADL assistance, a significant negative impact of the intervention on informal caregiving was detected on the level of informal assistance in IADL tasks. In New York City, while the project resulted in less IADL help for clients with fairly good functioning, no significant change was observed in the instrumental tasks for more poorly functioning clients, and caregiving in personal care tasks (ADL) was significantly increased due to participation in the project. These findings are depicted in Figure 3.1. The findings suggest that frailty level of elders is an important determinant of caregiving even in the context of receipt of formal services.

The availability of these project data makes possible the use of a replicative strategy (discussed below) with which to investigate the questions posed for this dissertation. Ideally, it would be valuable to examine the question in all three of the projects because each served a somewhat different component of the frail population, in somewhat different ways, in different geographical locations. Why would formal service receipt result in reduction or maintenance or increase of informal services among certain groups of frail elders but not other groups relative to similar elders who did not receive the special services? Unfortunately, preliminary investigation revealed that important caregiving measures (especially of burden and limitations) were not available in the South Carolina data set for most of the sample.[5] This project was well-established prior to the national evaluation and began supplementing data collection efforts late in the process. Therefore, explanatory model building is implemented with the projects which have

Figure 3.1

Impacts of Long-Term Care Projects on Informal Caregiving[a]

Project	Types of Tasks	
	ADL	IADL
South Carolina	no significant difference	no significant difference
San Diego	no significant difference	significantly less help
New York City	significantly more help	Better functioning -- significantly less help Poorer functioning -- no significant difference

[a] Significance of program impact refers to the statistical significance of a finding at a probability level $\leq .05$.

adequate data, the San Diego and New York City projects.

The San Diego and New York projects differed from each other in numerous ways which, as noted below, can be put to use in a replicative strategy. The discussion begins with a description of the two study samples to be used and is followed by a description of data sources and study variables. Next, the analytic approach is discussed.

Study Samples

The San Diego and New York City projects were two of five projects which were studied in depth for the national evaluation. Since this secondary analysis of data collected for the national evaluation is not primarily concerned with analyzing program impact, the study combines the treatment and comparison group members within each project to form the study samples. Differences between treatment and control or comparison groups on factors relevant to this research, problematic in a quasi-experimental study designed to detect program impact, are not problematic in the context of this research. Any increase in the range of variation increases the chances that, if relationships exist, they will be more likely to be detected. This study examines program participation as one factor which might influence caregiving but it does not assess program impact in the evaluative sense.

The Long-Term Care Project (LTCP) of North San Diego County was sponsored by the Allied Home Health Association and served as a non-profit, private broker of Medicare-waivered community-based services for the "at-risk" aged in the county. "At-risk" was defined to include: "those persons 65 and older who are in need of intensive or intermediate levels of home care as a result of a prior hospital admission; those who are in need of health or social support services at the intermediate or intensive level of care in order to avoid inappropriate placement in a long-term care facility; and those who require services at a maintenance or basic level of care in order to remain in their homes." Clients need to meet one or more of the following criteria to be eligible for the study:

- unable to maintain self at home without assistance in activities of daily living;
- at risk of long-term care institutional placement;
- subject to acute hospital admissions;
- having received home health services for unstable health problems, was now stable but required education and monitoring to maintain a stable state; and
- having a stabilized chronic or non-homebound status which restricted the client from receiving traditional home health services, but was in need of long-term care services.

Upon meeting eligibility criteria, elders were assessed and then randomly assigned to either a control or an experimental group. The program selected and served a moderately-impaired target group of community-residing elders with low probability of nursing home placement and relatively high hospitalization rates.

The New York City Home Care Project operated under the auspices of New York City's Department for the Aging, an Area Agency on Aging. It served clients in four sites in four boroughs of New York City. Two of the sites were in health agencies and two sites were in social service agencies. To be eligible for services, clients had to meet the following criteria:

- be over age 65 and subscribe to Medicare Part B;
- be chronically ill, functionally impaired, and/or mentally disabled;
- need assistance to go out of doors, up and down stairs, or with personal care to the extent that the participant needed between 8 and 20 hours of homemaker/personal care per week;
- <u>not</u> receiving Medicare-reimbursed services through a certified HHA on an ongoing basis; and
- reside within the catchment area.

Random assignment of clients to treatment and control groups was not possible in New York. Comparable comparison group members were sought from a variety of agencies in three boroughs of the city.

This program selected and served a highly-impaired population who also had a low probability of nursing home placement but only a moderate use of acute hospitals relative to other projects. It did not continue to serve participants once they required more than 20 hours of homemaker/personal care help per week.

In order to focus the analysis on an explanation of caregiving which is ongoing in nature, this study restricts the samples in a number of ways. First, the samples include only those study participants (both treatment and comparison group members) reporting at least one functional dependency in ADL or IADL over a one year period. Second, the sample is restricted to study participants who were residing in the community at the initial assessment. Third, only participants for whom substantial data are available at two points in time are included. Despite the attrition due to these factors from the larger study sample, the resulting samples (343 participants in San Diego and 294 participants in New York City) continue to be representative of the larger samples from which they were derived. The study samples are described in Chapter IV.

Sources of Data

All data for this study are derived from the multidisciplinary assessment instruments administered to all study participants by trained assessors.

In San Diego, data were collected by a nurse practitioner who assessed and reassessed treatment and control group participants three, six, 12, 18 and 24 months after initial assessment. Data were collected on demographic and functioning indicators as well as on health status and informal supports. In New York City, assessments and reassessments were administered by a nurse/social worker team at intake, at 6 months, and at one year following intake to project clients as well as to comparison group members. Data were collected on demographic characteristics, physical and mental functioning, service needs, and informal supports from the sample members' perspective. No data were collected from caregivers.

Indicators of Constructs

Variables available from each project's data set representing the major study factors are presented in Figure 3.2 and are described below. Comparable measures of constructs were sought in each project and there is a fair degree of overlap between the projects in this regard. Though the same exact measures may not be available in each sample, some indicator or indicators of the variable domain can be identified. Figure 3.3 summarizes the comparability of measures in the two projects. The strength of using different indicators of underlying constructs is part of the replicative strategy described later in this chapter. Demographic measures represent characteristics of the samples at the beginning of the study. All other variables are measured at the beginning of the study and again after one year.

Demographic Characteristics

Participants in each study sample can be similarly described in terms of age, sex, race, marital status, household composition, and income. In addition, number of years of education is available for the San Diego sample.

Figure 3.2

Study Variables and Coding

Variable Domain	Coding[a] San Diego	 New York City
DEMOGRAPHIC CHARACTERISTICS[b]		
Age	65-95	65-96
Sex	1. Male 2. Female	1. Male 2. Female
Marital Status	0. Not married 1. Married	0. Not married 1. Married
Ethnicity	0. Not white 1. White	0. Not white 1. White
Living Arrangement	0. Alone 1. With others	0. Alone 1. With others
Years of Education	Number of years	NA
Annual Income Bracket	1. To \$3,000 2. \$3,000 to \$4,000 3. \$4,000 to \$6,999 4. \$7,000 to \$9,999 5. \$10,000 to \$14,999 6. \$15,000 to \$19,999 7. \$20,000+	1. To \$2,400 2. \$2,400 to \$3,588 3. \$3,600 to \$7,188 4. \$7,200 to \$10,788 5. \$10,800 to \$14,388 6. \$14,400 to \$18,000 7. \$18,000+
PHYSICAL FUNCTIONING[b]		
Activities of Daily Living (ADL)[c] Index	0. No dependencies 1. One dependency 2. Two dependencies 3. Three dependencies 4. Four dependencies	0. No dependencies 1. One dependency 2. Two dependencies 3. Three dependencies 4. Four dependencies 5. Five dependencies

[a] In many instances, more detailed codes are available in the data base.

[b] Demographic characteristics are measured at baseline; other measures are measured at baseline and one year later.

[c] In New York, individual activities were coded 0. Independent and 1. Dependent prior to creating the summed index.

Figure 3-2 (continued)

Variable Domain	Coding[a] San Diego	Coding[a] New York City
ADL Activities: Bathing Dressing Feeding Toileting Transfer	0. Independent 1. Dependent	1. No need 2. Need met 3. Partially met 4. Unmet need 5. Met but burden 6. Partly met but burden 7. Unable to do activity 8. Refuses help
Instrumental Activities of Daily Living (IADL) Index	0. No dependencies 1. One dependency 2. Two dependencies 3. Three dependencies 4. Four dependencies 5. Five dependencies 6. Six dependencies	NA[d]
IADL Activities: Meal Preparation Shopping Medications Housekeeping Finances Transportation	0. Independent 1. Dependent	1. No need 2. Need met 3. Partially met 4. Unmet need 5. Met but burden 6. Partly met but burden 7. Unable to do activity 8. Refuses help
Days in Bed Past Two Weeks	0-14 days	NA
Time Ill in Past Six Months	NA	0. None 1. One week 2. 1-4 weeks 3. 1-3 months 4. 4-6 months
Katz House Confinement	1. Did not go out in past 2 weeks 2. Went out 1-2 times 3. Went out 3+ times in past 2 weeks	NA

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[d] The summed IADL scale in New York was not reliable.

Figure 3-2 (continued)

Variable Domain	Coding[a]	
	San Diego	New York City
Katz Mobility	1. Walks with or without mechanical assistance 2. Walks with personal assistance 3. Walks with personal and mechanical assistance 4. Does not walk	NA
Outdoor Mobility	NA	1. Able without difficulty 2. Able with difficulty 3. Not able on own 4. Unable
Mobility/Ambulation Rating	1. Independent 2. Dependent	0. No problem 1. Problem
Katz ADL Rating Scale	1. Independent in all 2. Independent in five 3. Dependent in bathing +one 4. Dependent in bathing, dressing, +one 5. Dependent in bathing, dressing, toiling +one 6. Dependent in bathing, dressing, toileting, transfer, +one 7. Dependent in all 8. Other dependency profile	NA
SELF-PERCEIVED HEALTH		
Total Health Status Score	3. Poor . . 6. Fair . . 9. Good	NA
Self-rated health compared to others	1. Poor 2. Fair 3. Excellent/Good	1. Poor 2. Fair 3. Excellent/Good
Health Change Six Months	1. Better 2. Same 3. Worse	NA

Figure 3-2 (continued)

Variable Domain	Coding[a]	
	San Diego	New York City
Health Interferes with Activities	1. Not at all 2. A little 3. A great deal	NA
MENTAL-EMOTIONAL FUNCTIONING		
MSQ Errors	0. No errors 10. Ten errors	0. No errors 10. Ten errors
Philadelphia Geriatric Center Morale Scale (PGC)	0. Good morale 17. Poor morale	NA
Life Satisfaction Index	NA	1. Very satisfied . . . 4. Very dissatisfied
Life Satisfaction Areas: Neighborhood Home Family Friends Social Contact IADL Arrangements ADL Arrangements Medical Care Personal Enjoyment Life in General	NA	1. Very satisfied 2. Fairly satisfied 3. Fairly dissatisfied 4. Very dissatisfied
SOCIAL RESOURCES		
OARS Social Resources Scale	0. Few resources . 13. Many social resources	NA
OARS: Number of People Know Well Enough to Visit	0. None 1. 1-2 2. 3-4 3. 5	NA
OARS: Frequency Talked on Phone in Past Week	0. Not at all 1. Once 2. 2-6 times 3. Daily	NA

Figure 3-2 (continued)

Variable Domain	Coding[a]	
	San Diego	New York City
OARS: Frequency Spent Time With Someone in Past Week	0. Not at all 1. Once 2. 2-6 times 3. Daily	NA
OARS: Has Someone to Trust and Confide In	1. No 2. Yes	NA
OARS: Frequency Felt Lonely	0. Almost never 1. Sometimes 2. Quite often	NA
Frequency of Contact With: Child not in household Other relative not in household Friend Neighbor	NA	0. None 1. <1/year, seldom never 2. 1/year 3. 6x/year 4. 1/month 5. 1/week 6. 5 days/week
Intimacy: Number of relatives and friends feels "really close to"	NA	0-20
Number of friends client feels "close to"		0-10
Number of relatives client feels "close to"		0-10
INFORMAL CAREGIVING		
Caregiving Level of Effort	0-117 (episodes in past weeks from 2 helpers in each ADL and IADL task)	0-40 frequency of assistance [up to daily] summed across 2 helpers in each ADL and IADL task)
Caregiving Extensiveness - Number of Different Types of Helpers	0. None 1. One 2. Two 3. Three	0. None 1. One 2. Two 3. Three
Number of Tasks with Caregiver Limitations/ Burdens	0 to 11	0 to 10
Number of Different Limitations	0. None . 3. Three	NA
Caregiver in Household	0. No 1. Yes	NA
GROUP MEMBERSHIP	0. Treatment group 1. Control group	0. Treatment group 1. Comparison group

Figure 3.3

Summary of Comparability of Study Measures in San Diego and New York City

Variable Domain	Measure Exists in Only One Site	Similar Measures in Both Sites	Identical Measures in Both Sites
Demographic Characteristics	Years of education (SD)	Annual income bracket	Age Sex Marital status Ethnicity Living arrangement
Physical Functioning	IADL index (SD) Days in bed past two weeks (SD) Time ill in past six months (NYC) Katz house confinement (SD) Katz mobility (SD) Outdoor mobility (NYC) Katz ADL rating (SD)	Mobility ambulation rating	ADL index Needs help with medications
Self-Perceived Health	Total health status score (SD) Health change in past six months (SD) Health interferes with activities (SD)		Self-rated health compared to others
Mental/Emotional Functioning	PGC morale scale (SD) Life satisfaction index (NYC)	MSQ errors	
Social Resources	OARS social resources scale (SD) Visit people (SD) Talk on phone (SD) Spend time with someone (SD) Felt lonely (SD) Frequency of contact with child, other relatives, friends, neighbors (NYC)	Trust and confide - feel close to	
Informal Caregiving	Different limitations (SD) Caregiver in household (SD)	Level of caregiving effort	Caregiving extensiveness Caregiving burden Group membership

Physical Functioning and Status

In terms of physical functioning and physical status, data are available in both projects on ambulation or mobility, continence, and ability to bathe, dress, feed and toilet (activities of daily living or ADL). Another important activity, ability to transfer from bed and chair, was not collected in the San Diego project but was obtained in the New York City assessment. The ADL variables form a Guttman type scale in which higher scores indicate greater dependency in ADL. Measures of overall health status are also available in both samples.

Instrumental Functioning

Both samples also contain data on Instrumental Activities of daily living: the ability to prepare meals, shop, self-administer medications, do light housekeeping and manage transportation. In San Diego, ability to manage finances is also available in the data set. The IADL variables are used to form a summary index in which higher scores indicate greater dependency in IADL.

Mental and Psychological Functioning

Variants of the Short Portable Mental Status Questionnaire (Pfeiffer, 1975) are available for both samples as a measure of cognitive functioning. Scores are reported as number of errors out of a possible ten, with higher scores indicating more cognitive impairment. Emotional functioning is measured in San Diego by the Philadelphia Geriatric Center Morale Scale which yields a total scale score as well as three sub-components: Loneliness-Dissatisfaction, Attitude Toward Own Aging, and Agitation. In New York City, respondents rate their satisfaction with nine areas of life as well as an overall life satisfaction rating. A summed index was constructed for this study of the ten items. On all these measures, higher scores indicate greater emotional problems.

Social Resources

Social networks are the source of active helping systems and as such are important in the study of social support. Data in both projects can be used to derive measures of the size and composition of the helping system though not necessarily of the wider social network. In San Diego, social resource data were gathered with the Duke University Social Resources and Activity Scale. The data include the number of people usually talked to, spend time with and can trust and confide in. An overall scale score is derived. In New York, information is available for the number of friends and relatives to whom respondents feel "really close", as well as frequency of contact with children, other relatives, friends and neighbors. Frequency of contact and number of different types of social contacts can also be used as an indicator of the complexity of the social network. Data were not readily available in San Diego which could be used to measure sample member embeddedness in a social network.

Informal Caregiving

Size and composition of the active helping network can be described. In San Diego, the presence of caregivers in the household is recorded. In New York City as well as in San Diego, living with others can be used as a proxy indicator of caregiving being readily available.

In this relatively young field of study, efforts are continuing in the search for a reliable and valid measure of the burdens and stresses associated with caregiving. At this time, no standardized measures exist. Some investigators rely on the frail elder's assessment of difficulties or limitations while others utilize ratings made by interviewers who become familiar with the caregiving situation. Clearly, a self-assessment of strain associated with the caregiving role by the caregiver herself is highly desirable. However, in studies which require that health and functioning measures be collected from frail elders themselves, it is difficult and expensive to also collect data from a parallel sample of caregivers (though dual data collection has been accomplished).

The measures of caregiver burden available in these two study samples reflect the lack of measurement standards. In San Diego, data are obtained from frail elder respondents. They were asked, for each ADL and IADL task, what were the major limitations to the helper if he/she needed to provide additional help. Two of the following responses (one for each of two possible helpers could be coded for each task:

- doesn't want to;
- work responsibilities;
- sickness, poor health, physical burden;
- poor accommodations;
- emotionally incapable;
- disrupts family life;
- unreliable; and
- distance

In New York City, the measure of burden relies on judgments made by the assessors after gathering information from the participant as part of the assessment care plan. For each ADL and IADL task, the assessor codes whether help is a burden to the caregiver.

The Dependent Measure: Level of Caregiving Effort

For this study, provision of social support is operationalized as level of caregiving effort, an indicator of the intensity or involvement of the active caregiving network in care provision. The terms involvement, intensity, or level of caregiving effort are more appropriate than the terms frequency or amount of help since each project has a distinct way of measuring caregiver involvement. Derivation of the measure for each project is presented below.

Of all the constructs used in this study, caregiving involvement or level of caregiving effort is the least well developed in terms of measurement. Distinctions have been made between the more objective aspects of involvement (the level of effort) and the strain or burden associated with that involvement, described above. Although detailed information on the amount of time spent in caregiving on particular tasks such as the actual number of hours spent helping, would be desirable (though error prone) for being able to detect change and stability, extensive detail is difficult and expensive information to obtain. A number of alternatives are typically used, for example, recording the number of tasks in which help is provided or the number of days in the week on which help is provided. San Diego and New York City (and South Carolina) obtained different levels of detail regarding level of caregiving effort.

Information on the level of caregiving effort approaches a true interval measure in San Diego. Frequency of help in the prior week (from .00 to 99.9 times) in each ADL and IADL task by a primary and secondary caregiver is recorded. Thus, it is possible to derive an overall interval level of caregiving effort for both informal and formal sources of help which represents units of discrete episodes of assistance in all ADL and IADL tasks. Of course, episodes can vary extensively in terms of duration and difficulty depending on the task and on the elders need.

In New York City, project coders combined the number of days on which help was usually received from up to two helpers in each ADL and IADL task. The combined level of effort measure indicates the number of days per week help was usually provided in each task using the following categories:

None
less than monthly
at least monthly
1 day/week
2-3 days/week
4-5 days/week
6 days/week
7 or more days/week

The level of measurement is ordinal with many categories[6]; the most frequent category is thus daily. Obviously, it is possible to under or overestimate the number of days due to the fact that some of the categories span two days, e.g., 2-3 days, 4-5 days. It is presumed that the extent to which days are underestimated is balanced by the extent to which they are overestimated in each task. An overall indicator of the level of effort is obtained by summing the coded frequency across the 10 ADL and IADL tasks.

The San Diego measure is the most exacting, sensitive but also most error prone measure. Episodes are summed for each task and for each source of help. It is clearly an indicator of *amount* of help. In New York City, the measure is more restricted. The help from multiple sources is added together resulting in numbers which are no longer interpretable in terms of days of help per week but which nonetheless are a gross indicator of level of effort. The New York City measure comes closer to tapping the *frequency* with which help is provided. Based on the variation in measuring how much or how frequently help is provided by members of the caregiving network, the measures are used in this study as representing the broader construct of level of caregiving effort of involvement.

Validity and Reliability of Measures

Reliability and validity of measures used for this secondary analysis derive primarily from the parent studies. Aspects of those studies and the participation of the national evaluator (BPA) as consultant to both projects contributes positively to measurement quality. Data in both projects were collected by nurses or nurses and social workers who were trained to use the study instruments. Instrumentation was similar if not exactly alike for many of the data items in each project. While interrater reliability was assessed within each project, no assessment of interrater reliability across projects is possible. Within these parameters, issues of validity and reliability are approached in two ways.

First, issues of measurement validity are addressed by examining relationships among study variables. Previous empirical work provides expectations about the ways in which constructs should and should not be interrelated. For example, measures of physical and mental functioning are expected to be moderately to highly related while the relationship between age and functioning is expected to be very low. These relationships are examined in Chapter IV.

Second, since validity is lessened by any lack of reliability (Seltiz, Wrightsman & Cook, 1976), a demonstration of internal consistancy of summative indices is a minimum requisite for confidence in the measure being used. In this case, reliability refers to ". . . homogeneity, or the extent to which an individual's responses to the various items or components of a measure are consistent" (Seltiz et al., 1976, p. 183). Measures of internal consistency give an indication of whether an individual's position is affected by the particular sampling of items. Cronbach's alpha, the reliability estimate used, is defined as the ratio of the variance of true scores to the variance of observed scores. Errors of measurement are assumed to be independent of true scores. "If all the variation in observed scores is due to errors of measurement, the reliability coefficient will be 0. If there is no error of measurement, the reliability will be 1" (Specht & Bubolz, 1977, p. 61).

Except for the measures of caregiver burden, life satisfaction and summed indicators of social resources in New York City, all the indices constructed for this study (ADL, IADL, PGC Morale, OARS Social Resources, and OARS Health Status) have been used in numerous studies with similar populations and are assumed to be meaningful. Results of analyses conducted to assess the internal homogeneity of the measures are presented in Table 3.1.

In San Diego, the measures of health status and social resources do not seem to tap unitary constructs and are not meaningful measures. The Cronbach alpha, which assesses the internal consistency of a set of items, is only .59 and .58 for the social resources and health status indices respectively. In contrast, the alpha for the ADL and IADL is 0.75 and for the PGC, .73, acceptable reliability coefficients. For New York City, three measures prove unreliable -- the index of IADL impairment (alpha = .25); the summed index of frequency of social contacts (alpha = .17); and the summed measure of extensity of social contacts (alpha = .23). Lack of reliability for the IADL index is probably due to the lack of variation among sample members. This sample is so impaired in these activities that, most and in some cases all of the sample fail to be able to perform these activities. The two efforts to

Table 3.1

Reliability of Summative Measures

	San Diego			New York City		
Summed Measure	Number of Cases	Number of Items	Cronbach's Alpha	Number of Cases	Number of Items	Cronbach's Alpha
Activities of Daily Living (ADL)	343	4	.75	254	5	.74
Instrumental Activities of Daily Living (IADL)	343	6	.75	254	4	.25
Total Health Rating	331	3	.58		NA	
Philadelphia Geriatric Center Morale Scale (PGC)	343	17	.73		NA	
Life Satisfaction Index		NA		250	10	.74
OARS Social Resources	343	5	.59		NA	
Frequency of Social Contacts		NA		269	4	.17
Extensity of Social Contacts		NA		269	5	.23
Caregiving Burden	343	11	.89	254	10	.79

summarize social resources are not standard approaches and no importance is attached to their lack of homogeneity. Items comprising the rejected indices will be used individually in further analyses.

ANALYTIC APPROACH

Given that this study is a secondary analysis of previously collected data, the research questions will be addressed in the context of the longitudinal pre-test/multiple post-test study design of the original projects. The basic aim of the study is to establish the relative contributions of a set of factors to caregiving involvement or intensity. The general analytic approach to be used is ordinary least squares regression.

First, the major analytic issues posed by the research questions are presented and aspects of the study design intended to mitigate analytic concerns are described. Next, the specific steps in establishing the conditions influencing caregiving and the generalizability of those relationships are detailed.

Major Analytic Issues

Two major analytic issues arise in this study: 1) how to incorporate change over time in both dependent and independent variables, and 2), how to reliably assess the *relative* contribution of independent variables in explaining variance in level of caregiving effort. The issues are discussed below.

Analyzing Residual Change

In this study, longitudinal data capturing change and stability in level of caregiving effort as well as in factors thought to influence caregiving involvement are available to help in the goal of explicating the how and why of caregiving involvement. Care must be used in harnessing these type of data in the service of explanation. For example, subtracting subsequent from initial measures, that is deriving simple change scores, leaves much to be desired for these purposes. Change scores exhibit undesired characteristics of low reliability, regression to the mean, and correlated error terms. These defects do not meet the assumptions required in ordinary least squares regression. A more appropriate way to incorporate change is described in the next section.

Problems associated with analyzing change over time in the dependent and independent measures are addressed in similar ways. Change in caregiving is analyzed using ordinary least squares regression by first removing the variance in caregiving at one year which is due to the initial level of caregiving. Change in caregiving is thus conceptualized as residual change, the variance in level of effort at one year which is unexplained by the level of effort at baseline. Among the independent variables, the difference between each independent variable at baseline and at one year is dealt with in a similar manner (described below). Scores at one year are regressed on scores at baseline which results in the creation of a single measure for each pair of items which is a deviation change score, or residual score. These are measures of how much a case has over- or under-changed relative to the change of all cases (Rummel, 1970). Further manipulations are applied to these data in the service of the other major analytic issue, explanation.

Explanation and Prediction

Kerlinger and Pedhazur (1973) state that "the question of the relative importance of variables is so complex that it almost seems to elude a solution" (p. 281). In this study, the relative importance of variables is of interest because the research emphasis is explanatory.

That is, where a relationship between an independent and dependent variable exists, the analytic task is to account for how and why it comes about. This approach is contrasted to interest in prediction in which independent measures are sought which together maximize the ability to account for variation in a dependent measure.

In the context of multiple regression analysis, regression coefficients are commonly used to assess the contributions of variables in the regression equation. However, use of these coefficients is valid only if the independent measures are not correlated with each other. In that case, each variable offers unique information not shared with any of the other independent variables and the proportion of variance in the dependent variable accounted for by each independent measure is the square of its correlation with the dependent variable (Kerlinger & Pedhazur, 1973). However, with data used in the social sciences, independent measures are typically correlated to some degree. Multicollinearity refers to the degree to which one or more independent variables are linearly related to one or more of the other independent variables included in the equation (Berry & Feldman, 1985). The regression coefficients are highly dependent on which measures are included in the equation and which measure is entered first, reducing the amount of variance able to be explained by the other variables, which amount is dependent on the independent measures relationships with each other. As Kerlinger and Pedhazur (1973) point out, "in general, when the independent variables are correlated, the more they are correlated and the later they are entered in the regression equation, the less the variance accounted for. Overall, multicollinearity results in unstable regression coefficients which may vary from sample to sample and which depend on other variables in the equation, computational inaccuracy, and difficulty making substantive interpretations. It is recognized that threats to analytic integrity from multicollinearity among independent measures is a matter of degree. The smaller the degree of multicollinearity, the less of a problem in analysis.

A commonly used approach to the problem of assessing the relative contributions of interrelated independent variables is to enter measures hierarchically either on the basis of theory or investigator interest. In this case, neither theory nor the research question posed are strong enough to justify an hierarchical approach. Neither are causal relationships amenable to a path analytic approach. Communality analysis (see Kerlinger & Pedhazur, 1973) apportions the variance in a dependent variable to that which is shared by independent variables as well as that which is unique to independent variables. The procedure is unwieldy with more than two or three variables and, it is possible to attribute a negative proportion of variance to independent measures, an unacceptable result. The research methods described below were chosen for their ability to help mitigate the analytic issues raised above.

In this study, recommendations made by Cohen & Cohen (1975) were all used to reduce the threat posed by multicollinearity: samples are of sufficient size (the samples utilized in this analysis each have comfortably large samples of approximately 300 subjects); independent measures are purged of redundancy and irrelevancy; single indicators of constructs are sought; and, the study is cross-validated or replicated in another sample. In addition, the study attempts to create independent measures for model building which are orthogonal. These steps are described below.

Seeking a Parsimonious Set of Independent Measures.

Wherever possible, summative indices and scales are used in the analysis. These indices must exhibit the attribute of internal homogeneity, that is, evidence must exist that the measure reflects a single underlying construct. Where reliability is lacking, based on Cronbach's alpha, individual items are examined for their relationship to caregiving. Bivariate relationships between the level of caregiving effort and potential explanatory variables at baseline are examined. Variables which are not statistically significantly related to caregiving (at the $p \leq .05$ level of significance) are excluded from further analysis.[7] Variables within the same domain which appear to be redundant are also excluded.

In order to diminish the effect that specific measures might have in the model and move measurement further along toward the level of constructs, the deviation change scores representing residual change between baseline and one-year for each independent measure (described above) are factor analyzed (see Rummel, 1970, for a discussion of the approach). One of the goals of common factor analysis is to reduce the common variance among a set of variables to a small number of linearly independent factors that reflect this variance (Rummel, 1970). Results of the factor analysis are examined for adequacy of the solution and meaningful interpretation. Rotation is used to clarify the factor structure. A desirable by-product of this procedure is that the resulting factors are not bivariately correlated with each other. Factor scores for each sample member are derived by weighting each variable (using the factor loading) comprising a factor proportionally to its involvement in a factor. The more involved a variable, the higher the weight. These composite variables (factor scores) are used in regression analysis. They have the desirable feature that "they embody phenomena with a functional unity" (Rummel, 1970, p. 152).8

The Strategy of Replication

In the past, replications have been thought of as exact in nature, duplicating an experiment using the same measures in another sample. Or, in the absence of exactness, an effort would be made to change but one aspect of the study in order to test its effect. Such a strict interpretation of replication is unnecessary and limiting. As Finifter (1975) points out, duplication and repetition are important but only partial aspects of replication. Typically, the study to be replicated has been completed; the replication follows as a reexamination. In this case, since multiple samples are available for analysis, the replication is concurrent. Furthermore, it can be characterized, according to Finifter (1975), as a virtual replication since the objective of the study is not to repeat another study identically but closely enough to see whether its results hold up against chance, artifact (p. 125) or, in this instance, geographic location. Since both projects operated in the early 1980's, a test of the model at different times is not possible. While some of the measures in the two original studies are the same, many of them are not. Different measures of the dependent variable are used as well. Contrary to viewing these departures as limiting, they can be seen in a positive light. As Finifter says:

> The advantage of introducing departures in samples and other method parameters is that the greater the number and range of variations among the studies in which the initial finding is successfully reproduced, the greater is our confidence in the initial finding . . . . Equally important is that the greater the range of variations among samples and other method conditions in which the initial finding is

> successfully and _un_successfully reproduced, the greater is our knowledge about the conditions that may _limit_ the scope of generalization of the finding." (p. 135).

Since the replication is a concurrent one, it is possible not only to comment about the robustness and generalizability of the findings, but to proceed with the analysis in each sample in a parallel fashion. Replicative failure can thus be attributed to different components and at different stages of analysis adding to our understanding of the phenomenon.

The foregoing procedures address the analytic issues raised previously such as multicollinearity and analyzing change, and focus the analysis on meaningful global constructs. It is recognized that the approach suggested is not the only one possible. Limitations of the approach include the possibility that, in using factor scores, the variance of the original independent variables which is associated with level of caregiving effort may not be retained as part of the factor scores. Should the factor structure not prove viable, an alternate strategy will have to be pursued. The approach described has merit for the stated goals in that it addresses key and multiple methodological problems.

Results of analyses described here are presented in the next two chapters. Chapter IV presents basic descriptive information and findings regarding the interrelationships among the study variables. Chapter V builds on these initial findings, and presents results of steps required to establish the factors and conditions influencing informal caregiving.

NOTES

[1] The author served as a senior research analyst on the evaluation.

[2] Most of these demonstration projects had been established for some period of time prior to the implementation of the national evaluation by BPA. Each demonstration project initially designed their own data collection forms and program evaluation. The BPA national evaluation effort had to build on these efforts. For projects which were well established at the outset of the national evaluation, little influence on data collection could be exerted. But for newer projects, BPA was able to influence data collection so that similar though not identical sets of core data were collected at a subset of the 13 sites.

[3] In the San Diego project an effort was made to incorporate changes in functioning into the analysis, but only in order to control for the effects of such change in the context of the impact evaluation.

[4] The use of the 05% probability level for identifying statistical significance of findings is not always appropriate, especially when it comes to the need to make policy decisions based on evaluation research. Depending on the "costs" of making a Type II error, accepting as true findings which are false, it may be reasonable for findings falling above the .05 level of statistical significance to considered so that new approaches to social problems are made possible.

[5] Available information is used to speculate on the South Carolina findings. Results are discussed in the conclusion.

[6] Though the dependent variable, level of caregiver effort, is technically an ordinal level measure, studies have demonstrated that such measures with sufficient categories can be confidently used to approximate interval measures in analyses.

[7] Using a strict level of significance (.05) yields a higher chance of rejecting a true hypothesis, not desirable for inferring social policy which might otherwise not attempt novel solutions to social problems. The goal of this research is to build a more general base of knowledge. Selecting the .05 probability level for making analytic decisions and drawing conclusions does not bring with it the connotations of "supporting the status quo". Rather, in this type of effort, it is preferable to reject an hypothesis which is actually true, than to accept an hypothesis which is actually false. For readers who are concerned that true relationships may be overlooked in the analysis, where significance levels fall between .05 and .10, these will be footnoted. Analysis will also be alert to those cases where relationships are a near miss in one study sample and are statistically significant (at the $< .05$ level) in the other.

[8] It is recognized that factor analysis can be misused. The use of factor analysis in this study rests on a firm methodological rationale as well as a base of expected theoretical domains.

IV. INITIAL FINDINGS

OVERVIEW

This chapter begins with a description of the study samples at the time of their respective baseline assessments. Variables in six domains are described: demographic characteristics, physical functioning, instrumental functioning, mental and psychological functioning, social resources, and informal caregiving support structure and burden. Descriptive statistics on the dependent variable, level of caregiving effort, are presented for baseline and for one year following the baseline measure. The relationships among variables are presented and described in order to 1) assess the construct validity of the variables and, 2) to ascertain which measures are related to informal caregiving at baseline.

PROJECT SAMPLE CHARACTERISTICS AT BASELINE

Demographic Characteristics

The two samples are similarly distributed on a number of demographic characteristics (see Table 4.1). In both samples, almost three-fourths of the members are female and equivalent proportions in each sample are currently unmarried (approximately 60%). More New York City sample members live with others while more San Diego sample members live alone. Each sample has almost the same mean age (approximately 80 years) though more of the New York City sample fall in to the 65 to 69 age bracket. The majority of sample members in San Diego and New York City have annual incomes between $4000 and $7000; San Diego has more members in higher income brackets. More affluent elderly, attracted to the climate, no doubt moved to San Diego upon retirement. Of note is the

Table 4.1

Demographic Characteristics of the Study Samples at Baseline

Variable	San Diego N	San Diego (%)	New York City N	New York City (%)
Sex				
Male	95	27.7	71	24.1
Female	248	72.3	223	75.9
	343	100.0	294	100.0
Age				
65-69	33	9.6	47	16.0
70-74	73	21.3	55	18.8
75-79	75	21.9	74	25.1
80-84	84	24.5	64	21.7
85+	78	22.7	54	18.2
	343	100.0	294	100.0
Mean	78.62		77.65	
Standard Deviation	6.67		6.85	
Race				
White	333	97.1	233	79.3
Non-White	10	2.9	61	20.7
	343	100.0	294	100.0
Marital Status				
Married	137	39.9	120	41.0
Widowed	170	49.6	141	48.1
Separated/Divorced	28	8.1	9	3.1
Never Married	8	2.3	23	7.8
	343	100.0	293	100.0

Table 4.1 (continued)

Variable		San Diego N	San Diego (%)	New York City N	New York City (%)
Years of Education					
0-8 years		98	28.6	NA	
9-12 years		134	39.1		
13-16 years		102	29.7		
17+ years		9	2.6		
		343	100.0		
Mean	11.22				
Standard Deviation	3.43				
Household Composition					
Alone		186	54.2	129	44.2
With Others		157	45.8	163	55.8
		343	100.0	292	100.0
Household Annual Income Bracket					
To @ 3,000		11	3.2	3	1.0
@ 3,000 - 4,000		18	5.2	13	4.4
@ 4,000 - 7,000		137	39.9	128	43.5
@ 7,000 - 10,000		64	18.7	104	35.4
@ 10,000 - 15,000		58	16.9	28	9.5
@ 15,000 - 20,000		21	6.1	9	3.1
@ 20,000+		11	3.2	2	.7
Unknown		23	6.7	7	2.4
		343	100.0	294	100.0

difference in racial composition of the two samples. Many more nonwhites comprise the New York City sample. Should a relationship between race and caregiving exist, it may be more likely to be observed in the New York City sample than in the San Diego sample. A measure of educational attainment is available only for the San Diego sample--equivalent proportions have an elementary, junior high and high school education.

Physical Functioning

Table 4.2 depicts the functioning of the two samples. It is evident that the New York City sample is much more impaired, accounting for their greater tendency to live with others. Only 8% of the New York City sample have no dependencies in ADL while over one-half of the San Diego group has no dependencies in ADL. Bathing is the activity with which most sample members need help in both samples. This finding confirms reports from Katz and his colleagues (reported in Kane and Kane [1981]), who have demonstrated that older people first require help with bathing and last with eating. Somewhat more New York City sample members have a problem with ambulation as compared to San Diego.[1] In San Diego, the majority (82%) can walk with or without mechanical assistance; almost three-fourths are rated as independent in mobility. On the measure of outdoor mobility available for New York City, only 1.4% are capable of going outdoors without difficulty; almost three-fourths of the sample cannot go outdoors on their own.[2] Compared to San Diego, fewer New York City sample members are rated as having no problem with ambulation (approximately two-thirds of the sample). Despite the relatively good functioning of the San Diego sample, self-reported health items indicate dissatisfaction with health: one-third of the sample rate their health as poor, half report that their health has gotten worse in

Table 4.2

Functional Status Characteristics of the Study Samples at Baseline

	San Diego		New York City	
Variable	N	%	N	%
ACTIVITIES OF DAILY LIVING				
% Independent				
Bathing		57.7		9.9
Dressing		74.1		35.3
Feeding		90.4		74.1
Transfer		NA		57.2
Toileting		82.8		58.0
Number of ADL Dependencies				
0	196	57.1	23	7.8
1	56	16.3	63	21.4
2	36	10.5	54	18.4
3	31	9.0	47	16.0
4	24	7.0	62	21.1
5	NA	NA	45	15.3
	343	100.0	294	100.0
Mean	.92		2.67	
Standard Deviation	1.86		1.57	
Mobility-Ambulation				
Walks with or without mechanical assistance	280	81.6	NA	
Walks with personal assistance	9	2.6		
Walks with personal and medical assistance	30	8.7		
Does not walk	24	7.0		
	343	100.0		

Table 4.2 (continued)

	San Diego		New York City	
Variable	N	%	N	%
Outdoor Mobility				
Able without difficulty	NA		4	1.4
Able with difficulty			74	25.3
Not able on own			208	71.0
Not able at all			7	2.4
			293	100.0
Mobility-Ambulation Rating				
Dependent/problem	97	28.3	100	34.0
Independent/no problem	246	71.7	194	66.0
	343	100.0	294	100.0
Number of Days in Bed in Past Two Weeks				
0	266	77.6	NA	
1-3	29	8.5		
4-10	24	7.0		
11-14	24	7.0		
	343	100.0		
Time Ill in Past Six Months				
None	NA		112	40.4
One week			40	14.4
1-4 weeks			45	16.2
1-3 months			40	14.4
4-6 months			40	14.4
			277	100.0
Self-Rated Health Compared to Others				
Poor	123	36.6	104	37.8
Fair	132	39.3	108	39.3
Good/Excellent	81	24.1	63	22.9
	336	100.0	275	100.0

the past six months and fully three-quarters say their health interferes with their functioning a great deal. Despite the actual differences in ability to function independently, similar proportions of each sample rate their health as poor, fair, or good/excellent compared to others their age. Individuals appear to separate how they <u>feel</u> about their overall health from how they are able to function.

Instrumental Functioning

While most of the San Diego members need some help with instrumental activities of daily living (only 7% are completely independent in meal preparation, shopping medications, housekeeping, heavy chores, finances, and transportation), <u>all</u> New York City sample members need help with at least one IADL activity (see Table 4.3). Fully 86% of the sample require help with four or five of the five tasks; the mean of the sample is 4.2 dependencies out of five activities (SD = .67). In contrast, San Diego members have a mean of 3.65 dependencies of 6 tasks (SD = 1.86). Because the summed measure of impairment in IADL activities did not form a reliable index in New York City it is not used in further analysis.

Mental and Emotional Functioning

Results are presented in Table 4.4. Though both samples have similar proportions with <u>no</u> MSQ errors, more of the San Diego sample exhibit a severe degree of mental impairment (7 to 10 errors) according to number of errors on the MSQ. The relatively high proportion of San Diego sample members with 7 to 10 errors is reflected in differences in mean MSQ scores in each sample. Mean number of errors for New York City are 1.19 (SD = 1.88) compared to San Diego with 1.71 errors (SD = 2.80).[3] Greater impairment in physical functional status is not reflec-

Table 4.3

Instrumental Functioning of the Study Samples at Baseline

	San Diego		New York City	
	N	%	N	%
INSTRUMENTAL ACTIVITIES OF DAILY LIVING				
% Independent				
Meal Preparation		43.1		5.3
Shopping		17.8		0
Medications		70.8		34.6
Housekeeping		15.2		3.2
Finances		57.7		NA
Transportation		16.9		3.0
Number of IADL Dependencies				
0	25	7.3	0	0
1	26	7.6	0	0
2	40	11.7	8	2.8
3	67	19.5	16	5.7
4	57	16.6	164	57.3
5	50	14.6	98	34.3
6	78	22.7	NA	NA
	343	100.0	286	100.0
Mean	3.65		4.22	
Standard Deviation	1.86		.67	

Table 4.4

Mental and Psychological Functioning of the Study Samples at Baseline

	San Diego		New York City	
	N	%	N	%
MSQ:				
Number of Errors				
0	183	53.4	153	52.0
1-2	85	24.8	92	31.2
3-6	40	11.6	41	13.9
7-10	35	10.2	8	2.6
Mean	1.71		1.19	
Standard Deviation	2.80		1.88	

Philiadelphia Geriatric Center Morale Scale[a]	Mean	SD	Mean	SD
Overall Score (range 0-17)	8.44	4.20	NA	
Life Satisfaction Index[a] (range 1-3.3)	NA		1.93	.50

[a] High score = poor morale/life satisfaction

ted in greater impairments in cognitive functioning. In fact, the more functionally impaired New York City sample has slightly better cognitive functioning than the San Diego sample.[4] Distributions on each sample's measure of morale or life satisfaction are also presented in Table 4.4. Since the measures are so disparate, the samples are not compared to each other. In San Diego, the sample mean on the Philadelphia Geriatric Center Morale Scale is 8.44 (SD = 4.20) of a scale total of 17. In New York City, the sample mean on the summed measure of Life Satisfaction is 1.93 (SD = .50) of a possible total of four.

Social Resources

Table 4.5 presents data on measures of social resources for San Diego and New York City. In San Diego, three-quarters report that they know five or more people well enough to visit them in their homes; half spoke daily on the phone to someone in the past week; and approximately one-third the sample reported spending time with a non-household member everyday in the past week. The majority (87%) report they have someone they can trust and confide in and almost half say they almost never feel lonely. In New York City, most members also report having friends or relatives they feel very close to and could call on for help. At the same time, in each sample, there appears to be a small group (perhaps 15% to 20%) who appear to have very limited social contact. It can also be recalled that approximately one-half of each sample is married and live with others (see Table 4.1). Unfortunately, data are not available in San Diego on contact with children or on number and type of persons in the social network. In New York City, approximately one-fifth to one-third of the sample have almost daily contact with either a neighbor, friend, child or other relative not living in their household.

Table 4.5

Social Resources of Study Samples at Baseline

Variable	San Diego N	San Diego %	New York City N	New York City %
OARS ITEMS				
Number of people know well enough to visit in their homes:				
Five or more	252	73.5		NA
Three to four	42	12.2		
One to two	26	7.6		
None	23	6.7		
	343	100.0		
Number of times talked to someone on the phone in the past week:				
Daily	167	48.7		NA
2-6 times	98	28.6		
Once	29	8.5		
Not at all	49	14.3		
	343	100.0		
Number of times spent time with someone outside the household:				
Daily	124	36.2		NA
Two to six times	166	48.4		
Once	31	9.0		
Not at all	22	6.4		
	343	100.0		
Has someone to trust and confide in?				
No	45	13.1		NA
Yes	298	86.9		
	343	100.0		
Frequency feel lonely:				
Quite often	79	23.0		NA
Sometimes	107	31.2		
Almost never	157	45.8		
	343	100.0		

Table 4.5 (continued)

Variable	San Diego		New York City	
	N	%	N	%
Frequency of contact with:				
Child not in household:				
None		NA	104	36.0
Seldom			100	34.6
Once a year			59	20.4
Six times/year			15	5.2
Once a month			4	1.4
Once a week			3	1.0
Almost daily			4	1.4
			289	100.0
Other relative not in household:				
None		NA	0	0
Seldom			41	14.4
Once a year			9	3.2
Six times/year			17	6.0
Once a month			62	21.8
Once a week			91	31.9
Almost daily			65	22.8
			285	100.0
Friend not in household:				
None		NA	0	0
Seldom			84	29.5
Once a year			7	2.5
Six times/year			10	3.5
Once a month			37	13.0
Once a week			97	34.0
Almost daily			50	17.5
			285	100.0
Neighbor:				
None		NA	0	0
Seldom			97	34.0
Once a year			2	.7
Six times/year			10	3.5
Once a month			23	8.1
Once a week			79	27.7
Almost daily			74	26.0
			285	100.0

Table 4.5 (continued)

Variable	San Diego N	San Diego %	New York City N	New York City %
Number of close friends:				
None	NA		99	34.9
One			55	19.4
Two			46	16.2
Three to four			44	15.5
Five or more			40	14.1
			284	100.0
Number of close relatives:				
None	NA		30	10.5
One			60	20.9
Two			71	24.7
Three to four			68	23.7
Five or more			58	20.1
			287	100.0

Informal Caregiving: Structure and Burden

At initial assessment, single helper networks were the norm in each sample, a finding common to the informal caregiving literature. Over one-half of each sample had only one helper (see Table 4.6); 16% had no help or had help from only formal sources; and almost one-third of each sample had 2 or 3 helpers. As expected, spouses, when available, were primary helpers, followed in frequency by a child. But, unrelated neighbors and friends were key helpers for one-third of the San Diego sample. In New York City, other relatives were more prominent as key helpers than unrelated friends and neighbors compared to San Diego. Table 4.6 also presents data on the number and percent of cases who mention receiving help from four different types of helpers (spouses, children, other relatives, and friends or neighbors). Approximately one-third of both samples receive help from spouses, and approximately one-third of both samples receive help from children. In New York City, a slightly larger proportion of sample members mention receiving help from other relatives (one-fourth) compared to San Diego (one-fifth). Conversely, receiving help from friends and neighbors is somewhat more common in San Diego (one-third of the sample) than in New York City (slightly more than one-fourth of the sample). Differences in prevalence of friends and neighbors versus other relatives in the helping networks of San Diego and New York City frail elders probably reflects situational factors more than differences in preferences of the sample members themselves. It may be more difficult to safely rely on neighbors and cultivate neighborhood friends in the changing neighborhoods of New York City. Friends may live too far away to feasibly render help on a daily or weekly basis. In contrast, the living environment of a retirement

Table 4.6

Informal Caregiving Network Characteristics at Baseline

Variable	San Diego N	San Diego %	New York City N	New York City %
Number of Types of Helpers[a]				
Caregiving Extensiveness				
0[b]	54	15.7	46	15.6
1	189	55.1	157	53.4
2	91	26.5	78	26.5
3	9	2.6	13	4.4
	343	100.0	294	100.0
Composition of Single Helper Networks				
Spouse	59	31.2	44	28.0
Child	53	28.0	44	28.0
Other Relative	16	8.5	27	17.2
Friend-Neighbor	61	32.3	42	26.8
	189	100.0	150	100.0
Composition of Dual Helper Networks				
Spouse and				
Child	18	19.8	21	26.9
Other Relative	13	14.3	13	16.7
Friend-Neighbor	19	20.9	6	7.7
Child and				
Other Relative	17	18.7	16	20.5
Friend-Neighbor	13	14.3	14	17.9
Other Relative and				
Friend-Neighbor	10	11.0	8	10.2
	91	100.0	78	100.0

[a] Four possible types: Spouse, child, other relative, friend-neighbor

[b] 0 denotes sample members with either <u>no help</u> or <u>only formal help</u>

Table 4.6 (continued)

Variable	San Diego N	San Diego %	New York City N	New York City %
Composition of Three Helper Networks				
Spouse, Child and Other Relative	3	33.3	3	23.1
Spouse, Child and Friend-Neighbor	3	33.3	5	38.5
Spouse, Other Relative and Friend-neighbor	0	0	2	15.4
Child, Other Relative and Friend-Neighbor	3	33.3	3	23.1
	9	100.0	13	100.0
Percentage of Networks with:				
Spouse		33.3		32.0
Child		32.1		36.1
Other Relative		18.4		24.5
Friend-Neighbor		31.8		27.2

community such as San Diego may be more conducive to the development of relationships with neighbors much like oneself who are more easily able to provide help. Of note is that in each locale, spouses and children are mentioned as sources of help by equivalent proportions of sample members. It is only when one goes beyond immediate family that environmental factors appear to influence the composition of helping networks.

A comparable measure of burden, the number of tasks in which there are limitations (San Diego) or burden associated (New York City) with providing help is available for each study sample. Distribution of the samples on this measure are reported in Table 4.7A. In San Diego, over one-third of the sample report no limitations of their caregivers with providing help in the 10 ADL and IADL activities. The average number of tasks with limits is 3 (SD = 3.27). Turning to New York City, only one-fifth the sample report no burdens associated with their caregivers providing help in the 10 ADL and IADL activities. The mean number of tasks with associated burden is 3.6 (SD = 2.6). The results suggest a somewhat higher degree of caregiver burden in New York City relative to San Diego. In table 4.7B are presented the number of different kinds of caregiver limitations, a measure available only for the San Diego sample, reported by San Diego sample members. Of the 217 sample members reporting some limitations (63.3% of the sample), 64% report only one type of limitation. The limitation mentioned most often is that the frail elder's illness, poor health or needs are too heavy a physical burden. The second most frequent type of limitation is that the caregiver's work responsibilities interfere.

LEVEL OF CAREGIVING EFFORT

The measures of level of caregiving effort available for each of the

Table 4.7A

Number of ADL and IADL Tasks in Which Caregiver Limitations/Burdens are Reported at Baseline

Number of Tasks	San Diego		New York City	
	N	%	N	%
0	126	36.7	61	20.7
1-2	61	17.8	58	19.7
3-4	56	16.4	75	25.5
5-7	52	15.2	79	26.9
8-10	48	14.0	21	7.1
	343	100.0	294	100.0
Mean	3.03		3.63	
Standard Deviation	3.27		2.63	
Median	2		3	

Table 4.7B

Types of Caregiver Limitations: San Diego

	Percent Reporting
Caregiver does not want to help	4.1%
Work responsibilities	16.9
Needs are a physical burden	37.0
Poor accommodations	12.0
Caregiver is emotionally incapable	2.0
Caregiving is disruptive to family life	7.6
Caregiver is unreliable	5.5
Caregiver lives far away	4.1

study samples differ not only in meaning but in level of measurement and interpretability as well.

Table 4.8A presents data on caregiving help received by San Diego sample members in 10 ADL and IADL tasks in the prior week and by New York City sample members in 10 ADL and IADL tasks in a typical week. San Diego sample members received a mean of 17.35 episodes of help in the past week (SD = 22.86). The maximum number of episodes at baseline is 117. However, it is clear that most sample members received a modest number of episodes of help: the median number of helping episodes is 5. After one year, the mean number of episodes of help for the sample had declined to 11.54 (SD = 16.75), and the median had dropped to 3. The maximum number of episodes is now 89.

In New York City, level of caregiving effort is an approximation of effort based on the number of times per week (up to daily) helpers provided care in 10 ADL and IADL tasks. Summing these frequencies across tasks and helpers results in a summed measure which loses interpretability in terms of frequency of help per week but which does capture degree of effort on the part of caregivers in the helping network.

Distribution of the New York City sample on the measure of level of caregiving effort is also presented in Table 4.8A. The maximum effort is 40 and the minimum is 0. The mean caregiving effort in New York City is 8.47 (SD = 6.65) while the median is 8.00 indicating that, unlike San Diego, sample members are more evenly distributed on the metric. Obviously, similar to San Diego, few sample members received extensive amounts of help. After one year, the maximum degree of caregiving effort has dropped from 40 units at baseline to 22 units at one year. The reduction may reflect an effect of the program on its participants

Table 4.8A

Summary Statistics for Level of Caregiving Effort at Baseline and One Year

Variable	San Diego Baseline	San Diego One Year	New York City Baseline	New York City One Year
TOTAL ADL AND IADL TASKS				
Maximum Caregiving Effort	117.00	89.00	40.00	22.00
Median Caregiving Effort	5.00	3.00	8.00	5.00
Mean Caregiving Effort	17.35	11.54	8.47	6.22
Standard Deviation	22.86	16.75	6.65	6.08
ADL Tasks				
Maximum Caregiving Effort	79.00	62.00	20.00	14.00
Median Caregiving Effort	0	0	0	0
Mean Caregiving Effort	6.26	4.13	2.60	2.18
Standard Deviation	13.44	9.82	3.60	3.14
IADL Tasks				
Maximum Caregiving Effort	49.25	34.25	20.00	16.00
Median Caregiving Effort	4.25	2.50	6.00	4.00
Mean Caregiving Effort	11.09	7.41	5.90	4.04
Standard Deviation	12.24	8.99	4.20	3.80

whereby informal caregivers could reduce their efforts on these tasks as the program provided services. Effort may have been reduced more by caregivers of heavily impaired clients or reductions may be distributed across all sample members equally. It can also be observed that the mean frequency dropped to 6.22 units and the median dropped to 5 units.

Table 4.8A also presents change in frequency of help for ADL tasks and for IADL tasks separately for each sample. Maximum level of caregiving effort decreases over time for each type of task (ADL and IADL) in each sample. Comparing changes in the proportion of sample members who receive help from informal sources for ADL tasks to IADL tasks, it can be observed that there is <u>less</u> change for ADL tasks. More sample members are likely to lose their informal help in tasks which are instrumental rather than personal.

Table 4.8B presents data on the proportion of sample members who received any help at all from informal sources at baseline and one year later. A similar proportion of New York City sample members as San Diego sample members received informal help with ADL and IADL tasks as baseline (82% and 83% respectively). Since the New York City sample is so much more impaired than San Diego it is likely that New York City elders who are not receiving informal help are receiving help from <u>formal</u> sources rather than not receiving help at all. After one year, a smaller proportion of the New York City sample was receiving help from informal sources in these ADL and IADL tasks (68%) than at baseline (83%). The change in proportion receiving informal help between baseline and one year represents a 90% decrease; in San Diego, the change in proportion of sample members receiving informal help between baseline and one year (from 82% to 76%) represents only a 33% decrease.

Table 4.8B

Proportion of Sample Members Receiving Informal Help:

Baseline and One Year

Variable	San Diego		New York City	
	Baseline	One Year	Baseline	One Year
Total ADL and IADL Tasks	82%	76%	83%	68.4%
ADL Tasks	31.8%	29.4%	48.6%	41.5%
IADL Tasks	81.9%	75.2%	82.3%	65.4%

Though the data indicates an overall decline in level of caregiving effort, in each sample, some sample members received the same or more help at one year relative to baseline. Table 4.9 presents information on the number of San Diego and New York City sample members with the same amount of help, less help and more help one year following the baseline assessment in all ADL and IADL tasks combined. While some frail elders in New York City and San Diego were receiving the same amount of help (20.4% and 12.8% respectively) or more help at one year (25.5% and 30.3%), the majority of sample members were receiving less help from informal sources at one year compared to baseline (54.1% and 56.9% respectively). San Diego caregivers were more likely to either increase or decrease their helping efforts relative to caregivers in New York City.

Change in helping episodes was differentially distributed for ADL as contrasted with IADL tasks in each sample (see Table 4.9). Informal helpers in each sample were more likely to reduce aid in instrumental rather than in personal care activities of daily living. Relative to San Diego, New York City helpers were more likely to change their helping efforts in ADL tasks, giving either more or less help. In contrast, relative to New York City, San Diego helpers were more likely to change their helping efforts in IADL tasks, giving either more or less help.

The decrease in the number of clients receiving help from informal sources of care observed in San Diego and in New York City (Table 4.8) may in part reflect the provision of formal care to treatment sample members by the projects. As a result, some informal helpers may have been able to reduce their efforts. The reduction in the proportion of clients no longer receiving help from informal caregivers after one year

Table 4.9

Change in Level of Caregiving Effort Between Baseline and One Year

Variable	San Diego N	San Diego %	New York City N	New York City %
TOTAL ADL AND IADL TASKS				
More Help	103	30.3	75	25.5
Same Help	44	12.8	60	20.4
Less Help	196	56.9	159	54.1
	343	100.0	294	100.0
ADL Tasks				
More Help	49	14.3	54	18.4
Same Help	213	62.1	157	53.4
Less Help	81	23.6	83	28.2
	343	100.0	294	100.0
IADL Tasks				
More Help	97	28.3	68	23.1
Same Help	45	13.1	71	24.1
Less Help	201	58.6	155	52.7
	343	100.0	294	100.0

is somewhat greater in the New York City sample (a 90% change) than in the San Diego sample. It is possible that the New York City program provided sufficient services such that informal care in these particular tasks was no longer required.[5] Of course, other factors could account for the change.

Informal caregivers in both samples were more likely to withdraw (Table 4.8A and 4.8) or reduce (Table 4.9) their efforts in IADL as contrasted with ADL tasks. Reducing informal aid in instrumental task areas may more feasible than reducing aid in personal care task areas. If a frail elder requires help with personal care, that care is needed on a daily and ongoing basis. Even if some formal care was used for personal care tasks, informal caregivers would likely need to continue their helping efforts as well. IADL tasks such as shopping, cleaning, and transportation tend to require intermittent help and non-intimate relationships and are more easily relegated to formal sources of care.

However, it was also observed that, relative to the San Diego sample, New York City sample members (who are more impaired and need more ADL help than San Diego sample members) were more likely to have less help from informal sources in ADL tasks (Table 4.9). There is no clear cut interpretation of this finding. Though overall use of nursing homes was low, it is possible that enough sample members entered nursing homes, where their needs would be met by formal sources, to account for the loss of help in ADL tasks. Provision of services to treatment clients by the Home Care Program were not extensive enough to account for the relatively greater loss of help in ADL tasks compared to the San Diego sample.

INTERRELATIONSHIPS AMONG THE INDEPENDENT MEASURES

Tables 4.10A and 4.10B present intercorrelation matrices of the independent variables in San Diego and New York City respectively. The matrices provide three particularly relevant types of information for this study. First, examining the interrelationships among the independent measures indicates the extent to which multicollinearity is present. Second, examining the matrices for expected relationships among variables permits an assessment of validity of the measures used. Third, examining the matrices enables an assessment to be made of redundancy within variable domains, information which can then be used to reduce the set of independent measures to be used to identify conditions affecting level of caregiving effort.

Observing the patterns of significant relationships in the tables confirms the high degree of relatedness among the variables. The steps designed to address multicollinearity (described in Chapter III) are indeed necessary to the analysis.

By and large, the variables used in this study are related to each other in expected ways suggesting that they are valid measures of the constructs they represent. Some unexpected associations, primarily in the New York City sample, introduce a cautionary note. These relationships are described below.

Among the demographic characteristics, expected relationships are observed for most factors in both samples. Thus, older sample members are more likely to have lower incomes, to be non-white, to be living alone, and, in San Diego, to be female. It is unclear why there is little to no relationship between sex and age in New York City. The

Table 4.10A

Intercorrelation Matrix of Independent Measures: San Diego[a]

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29
1. Age	--	.10	-.08	.01	-.04	-.11	-.16	-.00	.08	-.10	-.05	-.06	-.04	-.00	.13	-.03	-.14	.08	-.14	.00	.00	.12	.14	-.04	.06	.08	.04	-.04	.04
2. Sex		--	-.32	.05	-.33	-.03	-.21	-.21	-.24	-.02	-.02	-.11	-.16	-.19	.02	-.04	-.05	-.08	-.07	.03	.25	.11	.01	.10	-.11	-.06	.03	-.32	.10
3. Marital Status			--	-.00	.80	.04	.45	.35	.38	-.00	-.06	.17	.24	.35	-.14	.16	.15	.17	.18	.07	-.22	-.03	.02	-.11	.25	.31	.11	.62	.02
4. Ethnicity				--	-.08	.18	.08	-.01	-.10	-.03	.07	-.04	-.01	-.00	-.05	.05	-.04	-.12	-.05	.16	.10	.24	.03	-.05	-.07	-.06	.02	-.12	-.04
5. Lives Alone					--	-.01	.35	.42	.47	.07	-.11	.20	.25	.41	-.04	.08	.08	.28	.14	.04	-.34	-.12	-.06	-.13	.26	.30	.06	.66	-.07
6. Education						--	.22	-.02	-.01	.08	.08	.01	-.04	-.05	.03	.05	.04	-.10	-.08	.08	.10	.11	.04	-.13	-.04	-.03	-.03	-.04	-.09
7. Income Bracket							--	.23	.19	-.00	-.01	.12	.17	.21	-.18	.09	.21	.04	.12	.21	-.06	.03	.04	-.01	.08	.06	.01	.25	-.02
8. ADL								--	.63	.14	-.34	.56	.50	.95	-.02	.12	.16	.49	.27	-.15	-.51	-.09	-.15	.04	.56	.27	.20	.53	-.04
9. IADL									--	.10	-.31	.37	.39	.62	-.05	.14	.19	.49	.20	-.13	-.49	-.03	-.12	.04	.59	.46	.31	.61	-.07
10. Bed Days										--	-.23	.17	.11	.13	-.25	.18	.16	.09	.23	-.07	-.11	-.19	-.07	.07	.03	.02	.05	.13	.00
11. Housebound											--	-.34	-.29	-.35	.22	-.13	-.24	-.18	-.26	.25	.20	.09	.13	-.09	-.25	-.12	-.12	-.18	-.03
12. Mobility												--	.66	.61	.00	.05	.14	.31	.26	-.17	-.28	-.15	-.14	.05	.28	.21	.07	.29	.05
13. Mobility Rating													--	.55	-.08	.11	.17	.23	.29	-.05	-.25	-.06	-.10	.04	.29	.15	.09	.30	.07
14. Katz Index														--	-.00	.10	.16	.49	.27	-.15	-.50	-.06	-.16	.04	.55	.26	.22	.53	-.02
15. Overall Health															--	-.36	-.34	.09	-.39	.09	-.00	.09	-.01	-.13	-.02	.06	-.00	.00	-.07
16. Change in Health																--	.27	.03	.32	.02	.02	.06	-.04	.13	.08	.06	.07	.03	-.02
17. Health Interferes																	--	.02	.30	-.08	-.03	-.11	-.03	.11	.12	.06	.08	.10	-.06
18. MSQ																		--	.19	-.27	-.59	-.15	-.30	.14	.49	.20	.18	.37	-.05
19. POGC Index																			--	-.23	-.24	-.24	-.32	.55	.16	.04	.05	.15	-.05
20. OARS Visit																				--	.31	.34	.27	-.23	-.19	-.04	-.07	-.10	.01
21. OARS Talk																					--	.27	.27	-.09	-.45	-.15	-.14	-.49	.08
22. OARS Spend Time																						--	.17	-.09	-.09	.06	.06	-.15	-.01
23. OARS Trust																							--	-.25	.17	.03	-.03	-.09	.13
24. OARS Lonely																								--	.05	.02	.10	-.10	-.10
25. # Tasks with Limits																									--	.38	.67	.47	-.01
26. # of Helpers																										--	.43	.42	.09
27. # Different Limits																											--	.21	.07
28. Caregiver in Household																												--	-.07
29. Treatment Group Membership																													--

Table 4.10A (continued)

[a] See Figure 3.2 for coding

Correlations of .09 are significant at $p \leq .05$

Correlations of .13 are significant at $p \leq .01$

Correlations of .17 are significant at $p \leq .001$

Table 4.10B

Intercorrelation Matrix of Independent Measures: New York City[a]

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24
1. Age	--	-.00	**-.18**	.08	**-.10**	**-.28**	-.07	.01	-.08	.04	**-.13**	**.19**	**.20**	-.06	.09	-.07	-.03	.03	.02	-.00	**-.14**	**-.14**	-.04	.05
2. Sex		--	**-.32**	-.09	**-.25**	**-.28**	-.03	**-.25**	-.00	-.00	-.08	-.05	-.04	.05	-.05	**.10**	-.00	.01	**.14**	**.12**	**-.14**	**-.19**	**-.15**	.01
3. Marital Status			--	.02	**.74**	**.63**	**.20**	**.38**	-.02	-.01	**.23**	-.01	.07	-.09	.05	-.08	**.11**	.07	**-.11**	-.00	**.42**	**.34**	**.27**	-.09
4. Ethnicity				--	**-.17**	.00	.07	-.01	-.04	**.10**	-.09	**-.14**	.03	**.13**	-.07	**-.34**	**.13**	-.02	**-.27**	**-.13**	**-.24**	-.05	**-.23**	**.10**
5. Lives Alone = 0					--	**.46**	**.20**	**.33**	-.05	-.00	**.27**	.05	.09	**-.21**	**.16**	-.02	**.15**	**.12**	**-.14**	-.07	**.72**	**.36**	**.32**	**-.18**
6. Income Bracket						—	**.25**	**.30**	.05	-.00	**.24**	-.04	-.05	**-.15**	.08	-.01	**.10**	**.12**	-.00	.08	**.24**	**.30**	**.18**	-.09
7. ADL							--	**.41**	**.19**	**.15**	**.44**	-.07	.03	-.07	**-.10**	-.08	.04	-.01	-.01	**-.14**	**.18**	**.58**	**.12**	**-.24**
8. Needs Help with Meds								—	**.20**	**.16**	**.28**	.06	**.34**	**-.18**	.09	**-.12**	.05	-.03	**-.12**	**-.13**	**.26**	**.46**	**.17**	-.09
9. Time Ill in Past Six Months									--	.08	**.21**	**-.11**	.05	.02	-.01	.06	.04	-.06	.02	-.00	-.02	**.19**	.03	**-.10**
10. Outdoor Mobility										—	.08	.00	.01	**-.13**	-.09	-.06	-.04	-.03	-.00	-.07	.01	**.12**	.09	**-.14**
11. Ambulation											--	.04	.06	**-.14**	.07	-.01	.09	.01	.05	.03	**.24**	**.50**	**.23**	**-.22**
12. Overall Health													.06	**-.24**	.06	.06	-.02	.04	.04	.05	.07	.03	.01	-.00
13. MSQ Rating													--	**-.11**	.09	**-.10**	-.05	.00	**-.12**	-.04	.05	**.12**	.07	-.04
14. Life Satisfaction Index														--	-.08	**-.16**	**-.10**	-.09	**-.19**	.00	**-.22**	**-.27**	**-.21**	**.36**
15. # of Close Relatives															--	**.30**	**.31**	**.28**	**.10**	**.11**	**.21**	.06	**.19**	**.25**
16. # of Close Friends																--	-.01	**.11**	**.48**	**.30**	**.12**	-.06	**.22**	**.15**
17. Frequency of Contact: Children																	--	-.01	-.02	**-.10**	**.16**	.09	**.26**	.04
18. Frequency of Contact: Other Relative																		—	.05	.08	.03	.05	**.10**	-.02
19. Frequency of Contact: Friend																			--	**.34**	-.07	.05	**.16**	**.01**
20. Frequency of Contact: Neighbor																				--	-.05	-.03	.00	**.11**
21. # of Household Members																					--	**.33**	**.39**	**.19**
22. Caregiving Burden																						—	**.25**	**-.20**
23. Caregiving Extensity																							--	**-.16**
24. Treatment Group Membership																								--

Table 4.10B (Continued)

[a]See Figure 3.2 for coding

Correlations of .10 are significant at $p \leq .05$

Correlations of .14 are significant at $p \leq .01$

Correlations of .18 are significant at $p \leq .001$

relationship between ethnicity and age represents the well-known crossover phenomenon wherein non-whites in general have shorter life expectancies relative to whites, but non-whites who do survive tend to attain very old age. Age is a very imperfect predictor of physical and cognitive functioning. Thus, no relationships between age and measures of functioning are expected and, in San Diego, no associations are observed. However, in New York City, older sample members are more likely to have greater cognitive impairment.

Almost all the measures of physical functioning are strongly interrelated in each sample. In San Diego, poorer functioning on the measure of mental function (MSQ) is related to poorer morale as measured by the PGC morale scale as would be expected. However, an anomalous relationship between measures of cognitive and emotional functioning appears in the New York City sample where poorer functioning on the MSQ is related to <u>better</u> morale as measured by the life satisfaction index constructed for this study. This anomaly is explored further below.

Measures of social resources are related in expected ways in both samples. Having more of any type of resource tends to be related to having other kinds of social resources. Women and non-whites tend to have more extensive and intensive social networks, commonly found relationships.

Not surprisingly, the measures in the informal caregiving domain are moderately to highly interrelated in both samples. Thus, the more active helpers involved, the more tasks are reported to have helper limitations and, in San Diego, the greater the number of different limitations. The relationships in each sample parallel findings that living with others is necessitated by the need for help. Where frail elders live with others and have a caregiver in the household, more helpers are found in the helping system reflecting the more impaired status of those who live with others. In turn, a more extensive system is associated with more task limitations and with more different types of limitations.

In both samples, poor physical and mental functioning are associated with larger helping networks and concomitant helper burden.

For the most part, it is expected that physical, psychological, and social functioning will be interrelated to some degree. Though not perfectly related, poor physical functioning tends to be associated with poor mental and social functioning. To an extent, these relationships are observed in both samples. However, in New York City, physical functioning is not significantly related to cognitive functioning whereas in San Diego, the measures are highly related. In New York City, the measure of emotional functioning (life satisfaction) is related in anomalous ways to other measures. For example, more life satisfaction is associated with needing help with medications, impaired mobility and ambulation and more MSQ errors.

Despite the ability to create an internally homogeneous and reliable life satisfaction index, these findings raise questions about the meaning of the measure and thus its usefulness for further analysis. An effort was made to determine if perhaps the overall life satisfaction scale derived from 10 items had meaningful subcomponents. The items were subjected to principal components factor analysis with varimax rotation. Three fairly interpretable factors resulted: satisfaction with care arrangements (housework and personal care); satisfaction with home (family, neighborhood, home, and medical care); and satisfaction with social life (life in general, friends, contact and enjoyment). Each subcomponent was subjected to an analysis of internal homogeneity which resulted in low to moderate reliability estimates (.75 for satisfaction with care; .54 for satisfaction with home; and .69 for satisfaction with social life. However, examining the relationships between the subcomponents and the independent measures revealed similar anomalous findings. Thus, even if the overall measure or the subcomponents are related to level of caregiving effort, the meanings are unclear and would not contribute to explanation. It is possible that the data are flawed in some way not apparent to the investigator.

In only one case does the strength of an association clearly indicate that two measures are redundant: in San Diego, the two measures of ADL are so highly related (r=.95) that they are obviously measuring the same construct.

These findings suggest that some caution be used in interpreting findings using the New York City sample and in comparing findings between New York City and San Diego. A few anomalous and unexpected associations between measures were observed which suggest either measurement problems or that a somewhat unusual population is represented in New York City or in San Diego.[6] Further analyses proceed with this caveat in mind.

BIVARIATE RELATIONSHIPS BETWEEN INDEPENDENT MEASURES AND LEVEL OF EFFORT

This section describes the bivariate relationships between the independent variables and level of caregiving effort in each study sample. One purpose of this analysis is to continue with the task of seeking a parsimonious but powerful set of explanatory factors to be used in further analysis. Only measures which are significantly related to caregiving will be retained. Another purpose is to determine if relationships are replicated in each sample as hypothesized.

Table 4.11 presents correlations between level of caregiving effort at baseline and the set of explanatory measures for each study sample. Very similar patterns of relationships are observed in each study sample. In general, the strength of relationships are weaker in New York City than in San Diego probably reflecting the more restricted measure of level of caregiving effort in New York. Only independent variables bearing a statistically significant relationship with caregiving episodes are retained for further analysis.7 Within domains, measures are assessed for obvious redundancy.

Demographic Characteristics

In both samples, level of caregiving effort is related to care recipients' being male, being married, living with others, and, having a higher income. These relationships, except for the relationship with income, are typical of caregiving among the elderly. That is, care is often provided by wives to their husbands, and, those who need care are more likely to be unable to live alone. The relationship of income to receipt of informal help (higher income individuals are receiving more informal help than lower income individuals) might be explained by the association between income and use of institutional care. Those with higher incomes are able to remain in the community for longer periods of time and are thus more likely to be receiving extensive care at home. Those with higher incomes are also more physically impaired. It is not surprising that age is not related to receiving help in either sample. It is well known that age is an imperfect predictor of functioning and thus of need for help. There is evidence that different ethnic groups

Table 4.11

Correlations Between Level of Caregiving Effort and Explanatory Measures at Baseline

Variable Domain[a]	San Diego (N=343)	New York City (N=294)
Demographic		
Age	-.003	-.084+
Sex	-.270***	-.109*
Marital Status	.460***	.311***
Ethnicity	-.041	-.137*
Income	.231***	.170**
Lives Alone	.474***	.370***
Education	-.042	NA
Physical Functioning		
ADL	.788***	.383***
KATZ ADL	.750***	NA
IADL	.654***	NA
Needs Help with Medication	NA	.473***
Mobility	.471***	NA
Outdoor Mobility	NA	.188***
Mobility Rating/Ambulation	.452***	.329***
Housebound	.243***	NA
Bed Days in Past Two Weeks	.112***	NA
Time Ill in Past Six Months	NA	.070
Self-Perceived Health		
Overall Health	-.015	.042
Change in Health	.053	NA
Health Interferes with Functioning	.106*	NA
Mental-Emotional Functioning		
MSQ Errors	.477***	.177***
PGC Morale Scale	.179***	NA
Life Satisfaction Index	NA	-.201***
Social Resources		
OARS:		
Visit	.126*	NA
Talk on Phone	.484***	NA
Spend Time with	.108*	NA
Trust and Confidence	.121*	NA
Lonely	.037	NA
Number of Close Friends and Relatives:	NA	.089+
Number of Close Relatives	NA	.159**
Number of Close Friends	NA	-.006
Frequency of Contact With:		
Children	NA	.203***
Other Relatives	NA	.112*
Friends	NA	.001
Neighbors	NA	-.034
Number of Household Members	NA	.361***
Caregiver in Household	.677***	NA
Informal Caregiving		
Caregiving Extensity	.351***	.503***
Caregiving Burden	.526***	.482***
Number of Different Limitations	.164***	NA
Treatment Group Membership	-.041	-.085

* $p \le .05$
** $p \le .01$
*** $p \le .001$
\+ $p \le .10$

[a] Coding Key:
Sex: 1. Male, 2. Female. **Marital Status:** 0. Unmarried, 1. Married. **Ethnicity:** 0. Not white, 1. White. **Lives Alone:** 0. Yes, 1. No. **ADL, Katz, ADL, IADL:** high score = more impaired. **Needs help with needs:** 0. No, 1 Yes. **Mobility, outdoor mobility, mobility rating, ambulation, housebound, bed days, time ill:** higher score = more impaired. **Overall health:** high score = better health; change in health; health interferes with functioning. **PGC Morale Scale:** high score = poor morale. **Life Satisfaction Index:** high score = high satisfaction. OARS visit.

have stronger, more active helping networks (for example, see Cantor, 1979). In the New York City sample, being non-white is related to receiving more care from informal helpers. The small number of non-white sample members restricts the ability of ethnicity to explain differences in caregiving in the San Diego sample. Finally, years of education is not related to receipt of help in the San Diego sample.

These results suggest that for the purposes of model elaboration (discussed in Chapter V), subgroups based on sex, marital status, living arrangement, and race would be relevant for determining if the conditions related to level of caregiving effort are the same for these different types of frail elders.

<u>Physical Functioning</u>

As expected, there is a strong relationship between sample members' physical functioning and the help they receive. Each of the indicators of physical functioning in the San Diego sample is significantly related to the amount of caregiving received, though some measures are more strongly related than others. The lowest correlation is between caregiving effort and number of days spent in bed in the last two weeks (r = $\leq$ .001). The more impaired in the ability to perform ADL and IADL activities, and the more impaired on the Katz ADL index, the more help is received. The amount of help received is also significantly related to mobility as measured by self-assessment and by interviewer judgment, and houseboundedness. The poorer one's mobility and the more confined to one's house, the more help is received.

In New York City, the measure of ADL shows the strongest relationship to level of caregiving effort ($r=.383$, $p \leq .001$). Of the four IADL items with any variance, being impaired in the ability to self-administer medications is strongly related to level of caregiving effort ($r=.473$, $p \leq .001$). Both aspects of mobility, the capacity to negotiate outside of the home, and an overall index of problems with ambulation, are related to level of caregiving effort. As in San Diego, the more impaired, the more caregiving is received. Unrelated to level of caregiving effort in New York City is the respondent's assessment of the time he/she has been ill in the last six months. The measure may cover too great a period of time to be strongly related to current caregiving efforts.

Self-Perceived Health

While actual ability to perform activities is clearly related to receiving help, by and large, self-perceptions of ones health are not related in either of the study samples. The one measure common to both study samples, overall self-health rating, is unrelated to level of caregiving effort. In San Diego, more measures of self-perceived health are available. Since the summed score for the multiple self-perceived health items in San Diego did not prove to be reliable, it is not reported here. One of the individual health items was significantly related to the amount of help received -- the perception that health interferes with functioning ($r = .106$, $p = \leq .05$). The other items, perception of one's overall health and perception of change in health over the past six months were not related. That the only health self-perception related to receipt of help is itself defined in relation to functioning confirms the importance of the functioning construct for informal caregiving.

Mental-Emotional Functioning

In San Diego, two types of measures of mental-emotional functioning are available -- the MSQ measure of cognitive impairment and the PGC measure of morale and morale components. In New York City, a very similar MSQ measure is available. The indicator used to measure the construct of morale in New York City is a summed index of satisfaction with different aspects of life. As would be expected from the literature, indicators of these constructs are significantly related to receiving help in each sample. The more cognitively impaired and the worse morale, the more help is received. However, it will be recalled that New York City life satisfaction measure's questionable validity limits its utility within an explanatory framework.

In San Diego, the PGC subcomponent scores were also significantly related to caregiving episodes. Since overall emotional functioning is of greatest interest in this study and in view of the need to develop a parsimonious set of predictors, only the overall PGC measure is retained for model development in San Diego.

Social Resources

In both samples, having more social resources is related to receiving more help from informal caregivers.

In San Diego, individual indicators of social resources are reported since the summed measure of OARS social resources was not reliable. The individual items are related in the expected direction to the receipt of help. Thus, sample members who have people to visit with, talk to, spend time with, and have someone to trust and confide in receive more help. Of these indicators, the most strongly related was the number of people talked to in the past week. Feeling lonely, as measured by this single indicator, was not related to receiving help. And, as has already been pointed out, sample members who have spouses or who are living with others receive more help.

In New York City, a similar pattern of relationships is observed. Though the total number of friends and relatives respondents felt close to is not related to level of caregiving effort, the number of relatives felt close to is moderately related to caregiving. Having friends one feels close to is not significantly related to informal caregiving; this confirms that relatives form the core of these informal caregiving systems. Having someone to trust and confide in in New York City is associated with more help from informal sources as was also true in San Diego.

Informal Caregiving: Structure and Burden

Not surprisingly, the measures of extensiveness of the helping network, proximity of a caregiver, and caregiver limitations are strongly related to level of caregiving effort. The more different types informal helpers mentioned by sample members, the more help they receive. The relationship between caregiving involvement and burden is apparent in the high correlations observed between the number of tasks with which limitations are associated as well as, in San Diego, with the number of different limitations mentioned. The more help which is being received, the more tasks with limits and the more different kinds of limitations are mentioned. In San Diego, having a caregiver in the household is also significantly related to the amount of help received. While more help may be received in this situation because it is so readily available, it is also true that those with the greatest need for help are unable to live by themselves.

Treatment Group Membership

Given the quasi-experimental study design of the demonstration programs, treatment group membership, that is, being part of the demonstration program or being a comparison group member, should not be related at baseline to receiving help. There is no statistically significant relationship (at the .05 level) between group membership and receipt of help in either of the study samples. However, since this variable is of particular interest to the study, it is retained for further analysis.

SUMMARY

This chapter began with a description of the San Diego and New York City study samples in which extensive similarities were reported. Disparities between the samples are that New York City sample members are more physically impaired, more likely to be living with others, and to report more burden associated with caregiving. There was some indication that San Diego sample members are somewhat more cognitively impaired, and that the New York City sample contains a larger proportion of non-whites. Each sample contained members who received no informal help at baseline and those who received large amounts of informal help at baseline. Most of each sample received modest amounts of informal help. It does appear that fewer New York City sample members received informal care after one year relative to San Diego sample members. But, when the overall frequency or amount of care is examined, similar reductions in help are observed in each sample, and, some members of each sample were receiving more help after one year.

Examination of the interrelationships among independent measures and the comparison of findings between the two samples served to confirm the presence of multicollinearity and validated most measures. The results also generated some concerns, particularly with New York City where some unexpected and anomalous relationships were observed. As a result, the measure of emotional functioning (life satisfaction) will not be retained in further analysis and relative contribution of variables to change in level of caregiving effort will need to be interpreted cautiously.

Differences between the San Diego and New York City samples reported above, rather than placing a limitation on analysis, may provide more possibilities for detecting conditions which influence level of caregiving effort. Differences in proportions of sample members with any particular characteristic should not affect the relationships which exist between characteristics.

While some validity concerns were introduced as a result of comparing interrelationships among independent measures between the two samples, relationships between independent variables and level of caregiving effort were strongly replicated in each sample.

The next chapter builds on this set of findings in order to establish the relative contributions of factors to change in level of caregiving effort.

NOTES

[1] Other measures of mobility were not used due to the poor distribution of responses (e.g., more than 90% in any one category). However, the distributions underscore how impaired the New York City sample is in that more than 90% were categorized as impaired on each measure. The ambulation measure used here is a composite of different kinds of mobility and had a reasonable distribution of responses.

[2] Unfortunately, this variable was not used in the one year reassessment.

[3] Though the distribution of MSQ errors is somewhat unusual in the San Diego sample, the large majority of responses fall between 0 and 6 errors in each sample. The 10 per cent of severely impaired sample members should not be problematic in analysis.

[4] Although severe cognitive impairment can result in an inability to perform functional activities unaided, there is no concomitant expectation that physically impaired persons would also be cognitively impaired. Many health conditions which impede functioning do not affect cognitive abilities.

[5] Sample members may still be receiving help from informal caregivers, but not in these particular tasks. Caregivers may still be active but may be more active in arranging for services or providing emotional support.

[6] Other data for the 35 San Diego sample members exhibiting severe cognitive impairment were examined in an attempt to describe these sample members. They clearly are very physically impaired, in ADL as well as IADL functioning. There do appear to be a subset of 14 sample members who never leave their homes, who are bedbound, and who make no improvement on MSQ functioning over time. The small number of these possibly qualitatively different sample members should not affect analysis in an explanatory effort.

[7] Using the strict probability level of .05 resulted in excluding some measures, but at least one (and usually more) measure was retained in each conceptual domain. Using a more liberal probability of .10 would not have changed the results presented in any substantial way. Furthermore, with two samples, more evidence of the probable lack of relationship is provided. Where two similar measures are related to level of caregiving effort, they are related in both samples (except in one instance, ethnicity); where two similar measures are not related to level of caregiving effort, they are not related in both samples.

V. CONDITIONS AFFECTING THE PROVISION OF INFORMAL SOCIAL SUPPORT

OVERVIEW

A primary purpose of analysis to this point has been to provide information on which to base the selection of a parsimonious but powerful set of explanatory factors to be used in understanding the conditions under which the provision of social support is enhanced or diminished. First, efforts were made to identify the most valid and reliable indicators of constructs. Where possible, summed measures or indices were sought since, in general, they tend to be more reliable indicators of constructs than individual items. Where reliable scales could not be constructed, relevant individual items were evaluated for use. Excluded from the analysis due to lack of reliability were indices representing social resources and health status in San Diego, and IADL impairment and social resources in New York City (see Table 3.1). Based on a concern raised about the validity of life satisfaction indicators in New York City, those items are also dropped from further analysis.

In the previous chapter, two key types of information for selecting explanatory factors were presented: 1) redundancy of measures within domains and 2) relationship of measures to level of caregiving effort. In this chapter, a third criteria is introduced: whether or not sufficient change in independent measures has occurred for their <u>change</u> to contribute to change in caregiving.[1] These findings are discussed in the following sections followed by results of analyses designed to reduce the set of measures to a smaller number of underlying constructs. The relationship of these underlying constructs to participation in the demonstration program as a client or comparision group member is evaluated. Group membership and the derived constructs are analyzed using a combination of hierarchical and stepwise regression. The resulting models are then applied to subgroups of each sample to assess their applicability for different types of frail elders and situations.

SELECTION OF INDEPENDENT MEASURES

Redundancy and Relationship of Measures

Variables for each project were selected based on analyses described in Chapter IV, in which relationships between independent variables and level of caregiving effort, and redundancy within variable domains were examined, (and based on study interests in the case of treatment group membership). The variables used to explain change in level of caregiving effort for each project are presented in Figure 5.1.

Only measures which were statistically significantly related to level of caregiving effort are retained. Where two measures of a construct were related to caregiving as well as to each other and were clearly redundant, one measure was selected. In San Diego, both measures of ADL impairment were strongly related to level of caregiving effort and even more strongly related to each other. Since the non-Katz version was most strongly related to the dependent variable and since the non-Katz version is the more commonly used measure in long-term care research, it was selected for use in further analysis. The two measures of mobility in San Diego were also related to caregiving level of effort and appear to be redundant. The measure retained is the four category measure rather than the two category rating since the former may be able to capture finer gradations of change and therefore be more likely to contribute to explanation. The other measures were all significantly related to the dependent variable in each sample and were not clearly

Figure 5.1

Variables used to Identify Conditions Affecting Level of Caregiving Effort

Variable	San Diego	New York City
Physical Functioning:	ADL IADL Number of Days in Bed Mobility Number of Days Out of House	ADL Impairment in Meds Administration Ambulation
Self-Perceived Health:	Health Interferes with Functioning	NA
Mental-Emotional Functioning:	MSQ PGC Morale	MSQ
Social Resources:	OARS Visit OARS Talk on Phone OARS Spend Time with Others OARS Trust and Confidence	Frequency of Contact with: Children not in house Other relative not in house Number of Relatives Feels Close to
Informal Caregiving:	Caregiving Extensity Caregiving Burden Number of Different Limits	Caregiving Extensity Caregiving Burden
Treatment Group Membership:	Treatment versus Control Group	Treatment versus Control Group

redundant. None of the physical functioning measures used in New York City are clearly redundant with each other and thus, none will be excluded from further analysis on that basis. The measure of outdoor mobility has no counterpart at one year. Since change in the ability to manage outdoors cannot be assessed, and since one mobility variable remains for which change can be assessed and which is related to level of caregiving effort, the measure of outdoor mobility will be excluded from further analysis.

The demographic characteristics which were significantly related to level of caregiving effort are used in a later stage of analysis to identify and assess the relevance of the model (or models) developed to subgroups of the frail elderly population based on sex, marital status, race, and living arrangement.

Change Over Time Among Independent Measures

Earlier, it was proposed that one way to identify explanatory factors is to observe the changes in independent variables with which level of caregiving effort covaries. Table 5.1 presents the distributions of change over time in independent measures. Sufficient change is observed among these independent measures to anticipate their utility in pinpointing relationships between these factors and caregiving involvement. Moreover, data in the table show that when change does occur, improvement as well as deterioration takes place.

Overall, it appears that New York City sample members are less stable than San Diego sample members -- they are more likely to improve or deteriorate over time. Of note is the differential shift in caregiver burden which has occurred in San Diego and New York City. In San Diego, most sample members report <u>more</u> caregiver limitations at one year

Table 5.1

Changes Among Explanatory Measures From Baseline to One Year

	San Diego						New York City					
	Less/Worse		Same		More/Better		Less/Worse		Same		More/Better	
Variable	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)
Physical Functioning												
ADL	52	(15.2)	225	(65.6)	66	(19.2)	63	(21.4)	109	(37.1)	122	(41.5)
IADL	134	(39.1)	130	(37.9)	79	(23.0)	NA					
Needs Help with Meds	NA						58	(19.7)	201	(70.4)	18	(6.1)
Days in Bed	35	(10.2)	247	(72.0)	61	(17.8)	NA					
Ambulation/Mobility	23	(6.7)	290	(84.5)	30	(8.7)	42	(14.3)	210	(71.4)	42	(14.3)
Days Out of House	65	(19.0)	217	(63.3)	61	(17.8)	NA					
Self-Perceived Health												
Health Interferes with Functioning	36	(11.1)	209	(64.5)	79	(24.4)	NA					
Mental-Emotional Functioning												
MSQ	77	(22.4)	185	(53.9)	81	(23.6)	110	(37.4)	113	(38.4)	71	(24.1)
PGC Morale	106	(30.9)	46	(13.4)	191	(55.7)	NA					
Social Resources												
OARS Visit	52	(15.2)	207	(60.3)	84	(24.5)	NA					
OARS Talk	64	(18.7)	203	(59.2)	76	(22.2)	NA					
OARS Spend Time	69	(20.1)	157	(45.8)	117	(34.1)	NA					
OARS Trust	28	(8.2)	284	(82.8)	31	(9.0)	NA					
Frequency of Contact with:												
Children	NA						28	(9.8)	221	(77.0)	38	(13.2)
Relatives	NA						69	(24.3)	125	(44.0)	90	(31.7)
Number of Relatives Close to	NA						104	(36.7)	84	(29.7)	95	(33.6)
Informal Caregiving												
Caregiving Extensity	82	(23.9)	177	(51.6)	84	(24.5)	100	(34.0)	160	(54.4)	34	(11.6)
Caregiving Burden	60	(17.5)	96	(28.0)	187	(54.5)	225	(76.5)	61	(20.7)	8	(2.7)
Number of Different Limits	56	(16.3)	152	(44.3)	135	(39.4)	NA					

while most New York City sample members report less burden at one year. An increase in burden which presumably reflects the effects of stresses associated with ongoing caregiving is not unexpected. The reduction in burden in New York City suggests that formal care provision given to New York City treatment clients by the community-based program may have had a greater effect on their caregivers who, relative to San Diego caregivers, had more burden to begin with. Thus, reduction of burden may have been more possible in New York City than in San Diego.[2] The New York City sample also showed greater improvements in physical functioning which may have affected the degree of perceived burden.

A FACTOR ANALYTIC APPROACH TO MULTICOLLINEARITY AND CHANGE OVER TIME AMONG INDEPENDENT MEASURES

The analytic approach described in Chapter III called for a factor analysis and orthogonal rotation of deviational or residual change scores derived from baseline and one- year measures of explanatory factors. The approach is considered to be the most appropriate for incorporating change over time in the factors as well as for reducing, to the extent possible, the degree of multicollinearity among the set of independent measures. A beneficial by-product of the approach, if successful, is derivation of dimensions or constructs underlying the variables in the model. To the extent that a smaller number of variables adequately capture the information in the set of independent measures, then a more meaningful, parsimonious and powerful model can be derived. Furthermore, the procedure brings to the analysis more of an emphasis on general constructs of theoretical interest and away from variance due to measurement differences and measurement error. A cautionary note is required however: there is a possibility that in forming the factors, some of the variance of the component independent variables which is related to level of caregiving effort may be lost. That is, the new variables (factors) do not carry 100% of the information in the original set of variables.[3] It is hypothesized that variables will cluster with each other because they are related to some underlying factor. Since this is another phase of analysis in which replication is sought, factors with similar interpretations are hypothesized to describe the set of variables in each project.[4]

Procedures

Bivariate regression was used to create residual change scores in the following way. Each one year independent measure was entered into the regression as the dependent variable; the baseline measure was entered as the independent variable. The results provide residual scores representing the variance in the one year measure unexplained by the baseline measures. In this way, a set of residual scores was constructed for each independent variable. Summary statistics are presented in Table 5.2.

These scores represent change for each sample member relative to the change experienced by the entire sample. Each score represents the amount of positive or negative change (referring to the sign of the change) which is relative to the amount of change expected based on the baseline measure. For the purposes of clarification, suppose a sample member's baseline ADL score was 2, the predicted ADL score at one year in this sample is 1.64136. If the sample member's actual year one ADL score was 3, than the residual score (1.35864 or 3 - 1.64136) means that the sample member experienced more positive change over the year than would be expected on the basis of the prediction. In the case of the

Table 5.2

Summary Statistics for Deviational Change Scores[a]

Variable[b]	San Diego Minimum	San Diego Maximum	San Diego SD	New York City Minimum	New York City Maximum	New York City SD
ADL	-3.0884	3.0822	.9341	-3.9169	4.6128	1.3088
IADL	-5.3750	3.4756	1.2312		NA	
Help with Meds		NA		-.8163	.6865	.4397
Days in Bed	-4.4999	13.4260	3.0808		NA	
Mobility/Ambulation	-2.0036	2.8621	.7027	-.5918	.7835	.4409
Days Out of House	-1.7090	1.2392	.6502		NA	
Health Interferes with Functioning	-2.5768	.9403	.7234		NA	
MSQ	-8.3536	9.6003	2.0259	-6.1829	9.2759	1.8508
PGC Morale	-10.0304	13.1629	3.6154		NA	
OARS Visit	-2.5815	1.5130	.8345		NA	
OARS Talk on Phone	-2.7177	2.4325	.7939		NA	
OARS Spend Time	-2.2861	1.8888	.8852		NA	
OARS Trust	-.8960	1.1265	.9985		NA	
Frequency of Contact with:						
Children		NA		-5.8112	5.6166	1.0971
Other Relatives		NA		4.2207	3.2663	1.3859
Number of Relatives Feels Close to		NA		-4.8418	8.3667	2.2860
Caregiving Extensiveness	-1.4700	2.5300	.7093	-1.7664	2.1518	.6133
Caregiving Burden	-3.1206	9.0509	1.6995	-.4385	8.8216	1.0302
Number of Different Limits	-.9768	2.3995	.6564		NA	

[a] Since these are deviation scores, the mean is 0

[b] See Figure 3.2 for coding

ADL index, because higher scores indicate greater impairment, the relative change translates to somewhat more impairment over the year than might have been expected in the sample. The change represented by the scores are intrinsically tied to scores of the particular sample -- change is change relative to how all other sample members changed. It will be noted that scores range on a scale from most negative to most positive change; mid-range scores indicate little positive or negative change relative to other sample members. In fact, the mean of these scores is zero. (See Rummel, 1970, pp 234-239 for an explication of alternative ways of measuring change.)

In order to determine if this set of information could be adequately described by a reduced set of descriptors, these residual or deviation scores were then subjected to principal components factor analysis. Varimax rotation was implemented in order to maximize the distinctness of the factors and clarify the structure.

Results

Results of these analyses are presented in Table 5.3A (San Diego) and 5.3B (New York City). In San Diego, approximately one-half the variance of the variables subjected to the analysis is captured by four analytic factors.[5] The first factor, describing functional and cognitive impairment, includes houseboundedness, ADL, mobility, days in bed, and the mental status measure. While it is expected that physical and mental impairment are related, the constructs are usually thought of as distinct. The finding that physical and cognitive functioning are intermixed in the San Diego sample may reflect a pull exerted by the disproportionately large number of sample members with moderate to severe cognitive impairment. The factor captures 23.3% of the variance

Table 5.3A

Factor Loading Matrix:

Varimax Rotation of Principal Components

San Diego

Variable	Factor 1	Factor 2	Factor 3	Factor 4	Total
	Physical-Cognitive Functioning	Socio-Emotional Functioning	Caregiving Burden	Caregiving Extensiveness+	
Deviational Change:					
Housebound	**-.71875**	.07039	.02141	.04137	
ADL	**.71318**	-.07858	.20376	.24418	
Mobility	**.67093**	-.06424	.10888	.04000	
Beddays	**.53054**	-.15986	-.01275	.02530	
MSQ	**.46045**	-.23207	-.04222	.27234	
Spend Time With	.04979	**.75639**	.09435	-.15333	
Visit	-.14424	**.69368**	.01850	.09784	
Trust	-.16926	**.60000**	-.11774	.08620	
PGC Morale	.23408	**-.54996**	.09938	.38205	
Talk on Phone	-.37605	**.46874**	-.13734	.00637	
Number Different Limits	.04967	-.05386	**.89421**	.03813	
Caregiving Burden	.10993	-.00309	**.88581**	.02880	
Health Interferes	.05976	.14063	-.11046	**.77768**	
IADL	.28079	-.21533	.27483	**.47388**	
Caregiving Extensity	-.01139	-.04531	.40326	**.40401**	
Eigenvalue	3.49273	1.76858	1.34224	1.07318	
Percent of Variance	23.3	11.8	8.9	7.2	51.2

Table 5.3B

Factor Loading Matrix:

Varimax Rotation of Principal Components

New York City

Variable	Factor 1 Physical Functioning	Factor 2 Caregiving Burden+	Factor 3 Caregiving Extensiveness+	Factor 4 Cognitive Functioning	Total
Deviational Change:					
ADL	.81371	-.02439	-.05083	-.00194	
Ambulation	.81199	-.05733	-.03886	-.01291	
Help with Meds	.53570	.30684	.11689	.45805	
Contact with Relative	.08782	-.68757	.15296	.35726	
Caregiving Burden	-.12290	.68598	.10893	.28643	
Number of Close Relatives	-.06086	.35085	**.69862**	.09623	
Caregiving Extensity	.20483	.26377	**.58119**	.05088	
Contact with Child	-.15509	.01607	**.55547**	-.19310	
MSQ	.01072	-.03310	-.11461	**.83641**	
Eigenvalue	1.81823	1.26456	1.14767	1.07491	
Percent of Variance	20.2	14.1	12.8	11.9	58.9

in the variable set. The second factor describing social and emotional well-being includes PGC morale and the social resources items. Improvements in morale were consonant with improvements in social contacts. The factor accounts for 11.8% of the variance. The third factor, caregiving burden, includes the measures of number of tasks with limitations and number of different limitations and accounts for 8.9% of the variance in the set. The fourth factor includes change in IADL functioning, change in the perception that health interferes with functioning, and change in the number of helpers in the helping network. Deteriorating IADL, increased perception that health interfered with functioning, and more types of helpers in the helping network after one year are related to an underlying construct. The question might be asked as to why change in system extensiveness was linked with change in IADL impairments but not with change in ADL impairment. Referring back to Table 5.1, it is noted that the primary type of change which occurred in this sample was experienced in the need for help in IADL tasks. The helping network was activated in response. The factor accounts for 7.2% of the variance.

The factor structure in New York City is similar in a number of respects to San Diego though a number of differences are also apparent. Four factors also describe the information in the New York City variables but in this case, the factors capture almost 60% of the variance, a slight improvement over San Diego. In New York City as in San Diego, the first factor can be described as a functional impairment factor comprised of impairment in ADL, mobility, and the ability to self-administer medications. It accounts for 20.2% of the variance in the variable set, similar to the amount of variance accounted for by the first factor in San Diego. Cognitive functioning was not a part of this construct as it was in San Diego. The second factor in New York City is comprised of two items, caregiver burden and frequency of contact with relatives (loaded in opposite directions) -- an increase in contact with relatives is associated with a decrease in tasks with which caregivers experience burden. As reported in the literature, perhaps relatives are providing emotional support to caregivers. The change in burden in the helping system is distinct from any change which occurred in the extensiveness of that system. The factor accounts for 14.1% of the variance. The third factor includes the number of helpers in the caregiving network, frequency of contact with a child and the number of relatives to whom one feels close (12.8% of the variance). The clustering of these variables suggests that, at least from the sample member's perspective, activating the helping network is not anathema to good rapport with family. It is not known which types of helpers were added. Finally, cognitive functioning is represented in the fourth factor by MSQ, the only indicator of this construct. This factor accounts for 11.9% of the variance.

It is apparent from the results of a factor analysis of variables representing key domains such as physical functioning, cognitive functioning, instrumental functioning, social resources, and caregiving structure and burden, that one underlying structure is inadequate to describe relationships for two samples of frail community residing elders. Though both samples are similar in many ways (age, sex, marital status) and in general typify those elderly characterized as frail by community programs, the differences which were observed were extensive enough or sufficiently qualitatively different to indicate sub-populations which cannot be adequately described along the same dimensions.

Physical impairment is a powerful descriptor, capturing the majority of variance represented by variables in both samples. However, in San Diego, the descriptor includes cognitive as well as physical impairment. Perhaps the intermingling of these two aspects of functioning is explained by the inclusion of San Diego sample members with significant mental impairment. Though the mean number of errors on the MSQ were similar in San Diego and New York City, San Diego had more sample members with moderate to high errors.

In San Diego, social contacts and caregiving were separate constructs while in New York City, aspects of caregiving are mixed with aspects of social resources. The admixture of caregiving items with social resources items in New York City may reflect the New York City sample's more impaired status. With severely impaired elders, social contacts and relationships may lose some of their purely social content and be increasingly bound up with necessary caregiving tasks.

Differences in level of severity between the samples may also underlie the composition of the fourth factor in San Diego. Change in extensiveness of the helping network was related to the same underlying factor as change in IADL impairment whereas in New York City change in number of types of helpers was associated with change in the number of close relatives and frequency of contact with a child. The nature of IADL tasks (e.g., shopping, cleaning, etc.) is that anyone can do them. However, the nature of ADL tasks (e.g., feeding, bathing, etc.), involves personal care of the body and calls for a degree of intimacy between frail elder and helper. It is more difficult to draw more helpers into the system for these needs. It is also possible that increased closeness may result from the need for personal care. At the same time, the distinction between contacts which are clearly social and contacts which are clearly caregiving may be lost. With severe impairment, caregiving is such an ever present need that social contacts <u>become</u> caregiving contacts.

Despite the finding that different variables are linked with <u>extensiveness of the helping system</u> (number of different types of helpers) and <u>caregiver burden</u> in each sample, the number of different types of helpers and the burden associated with caregiving belong to distinct underlying constructs in both samples.

Degree of physical impairment and type of physical impairment clearly differentiates the samples. Indeed, the two groups probably do not represent a single population of frail community residing elders, but represent distinct groups within the older population. The severity of impairment which differentiates the groups results in subsequent differences in the importance of other conditions related to informal support. In the severely impaired New York City sample, caregiver burden followed by helping network extensiveness are the second and third most important dimensions underlying the information contained in the variables used to describe the sample. In the moderately impaired sample in San Diego, socio-emotional functioning remains a relevant construct and is second in importance only to physical impairment in restructuring the information about the sample. Only after this construct do the dimensions of caregiver burden and helping network extensiveness appear. In each project sample, caregiving burden is more important relative to the extensiveness of the helping system. Social functioning is not present as a discrete construct in New York City but is intermingled with aspects of helping. The role of cognitive functioning is dissimilar in the samples. In San Diego, it fails to describe a discrete construct as it does in New York City. In the latter project, selection of project clients appears to have been restricted to those without extensive cognitive impairment and who could be served within the hourly limits of the program.

EXPLAINING CHANGE IN LEVEL OF CAREGIVING EFFORT: ANALYSIS OF COVARIANCE

Recognizing the limitations inherent in using factor scores and in the different constructs apparently represented in the two samples, the analysis proceeds toward establishing the relative contributions of the explanatory constructs for the level of caregiving effort or involvement for each sample. Before proceeding, it will be remembered that sample members in the two projects were assigned to one of two groups: a treatment group receiving a special program of services and case management, and a comparison or control group which continued to receive whatever services were available in the traditional system of care in their communities. Thus, findings concerning the relationship of the four factorially derived constructs to caregiving involvement might reflect features of the samples and the purposes of the original study from which they were drawn.

Table 5.4 presents the correlation coefficients between group membership and the four derived factors. Examining these results (and the mean deviation scores for the two groups) indicates that participation in the demonstration program appears to be moderately related to changes in physical functioning and changes in helping network burden in the New York City sample.[6] Treatment group members primarily maintained their functional levels while comparison group members improved in functioning

Table 5.4

Correlation Coefficients: Group Membership[a] and Explanatory Factors

San Diego			New York City		
	r	p		r	p
Physical-Cognitive Functioning	.007	.450	Physical Functioning	-.171	.003
Socio-Emotional Functioning	.074	.091	Caregiving Burden+	.314	.000
Caregiving Burden	.061	.137	Caregiving Extensity+	-.046	.229
Caregiving Extensity+	-.018	.376	Cognitive Functioning	.074	.117

[a] Group Membership: 0 = Treatment Group; 1 = Comparison Group

over time. Treatment group members in this sample were the more impaired at baseline. A more significant relationship is observed with burden in the network: burden among the comparison group was maintained or increased while burden among the treatment group decreased over time. It is possible that the New York City program had a positive affect on caregiver burden. In contrast, little apparent affect of program participation on the derived constructs is observed in the San Diego sample. The strongest relationship observed is with the construct describing socio-emotional functioning (a trend).

Because the relationship with group membership could affect the ways in which the derived constructs are related to caregiving involvement, group membership is entered hierarchically in the regression equation. The baseline measure of level of caregiving effort is also entered hierarchically into the multiple regression equation in order to remove variance in year one level of caregiving due to level of caregiving at baseline. In effect, the analysis goes go on to explain caregiving level of effort once initial level of effort and group membership are accounted for. Factor scores based on the loadings of variables on the derived factors are then entered into the equation in a forward entry method in order to determine which constructs will make statistically significant contributions in conjunction with the other constructs. Interaction terms between the factors and group membership are added as a group last to test whether the relationship between provision of care and the factors varies depending on participation in the demonstration program.

Results

Results of the regression analysis for each sample are presented in

Table 5.5. Similar relative contributions of group membership to caregiving involvement (once initial level of caregiving is accounted for) are observed in each sample. However, the direction of the effect is not the same in the two samples. Being in the comparison group is associated with increased caregiving involvement in the San Diego sample while it is treatment group membership which is associated with increased caregiving involvement in the New York City sample. The factor scores for the four derived constructs are entered into the equations next using a forward entry method.[7]

Recalling the literature reviewed in Chapter II, it was expected that physical impairment or the need for help would be positively related to caregiving involvement; increasing burden of care was expected to decrease the amount of help provided; having more social resources was expected to increase the amount of care provided; and being a happier person without cognitive problems was expected to increase the amount of care. For a variety of reasons, these relationships were not born out in the analyses presented here.

Before interpreting the contributions of the factors to caregiving involvement in each sample, the contribution of the set of interaction terms must be evaluated. In the San Diego sample, the set of interaction terms does not add significantly to our ability to explain caregiving involvement and the contribution of the factors can be assessed. However, in the New York City sample, the set of interaction terms does make a significant contribution indicating that the relationship between one or more of the factors and caregiving involvement is not the same for treatment group members as it is for comparison group members. Examining statistics for the individual interaction terms indicates that

Table 5.5

Analysis of Covariance Results for Change in Caregiving Level of Effort

	San Diego				New York City				
Variable	Beta	R^2 Change	Cummulative R^2	F of the Change	Variable	Beta	R^2 Change	Cummulative R^2	F of the Change
Covariate (1)					Covariate (1)				
Baseline Level of Cargiving Effort	.701	.491	.491	329.010***	Baseline Level of Caregiving Effort	.570	.325	.325	140.330***
Covariate (2)					Covariate (2)				
Group Membership[a]	.085	.007	.498	4.880*	Group Membership[a]	-.082	.007	.331	2.940+
Factors (3)					Factors (3)				
Physical-Cognitive Impairment	.200	.039	.538	28.891***	Physical Impairment	.274	.071	.402	34.521***
Caregiving Burden	.157	.024	.562	18.421***	Caregiving Extensiveness+	.187	.033	.436	16.966***
Caregiving Extensiveness+	.115	.013	.575	10.506***	Caregiving Burden+	.185	.031	.466	16.576***
Interaction Effects (4)		.007	.582	1.361	Interaction Effects (4)		.022	.488	3.035*
Factor 1 X Group					Factor 1 X Group				
Factor 2 X Group					Factor 2 X Group				
Factor 3 X Group					Factor 3 X Group				
Factor 4 X Group					Factor 4 X Group				

[a] Group Membership: 0 = Treatment Group; 1 = Comparison Group

* $p \leq .05$
** $p \leq .01$
*** $p \leq .001$

a differential relationship exists between caregiving involvement and changes in physical functioning for treatment and comparison group members. The effect of changes in physical functioning on caregiving must be interpreted differently depending on whether or not the sample member participated in the program of community services. Comparison group members improved their functional status while treatment group members maintained their functional status. Because of the differential effect on this important factor, analyses proceed separately for treatment and comparison group members in the New York City sample. Results appear in Table 5.5A.

In San Diego and among New York City program participants, the most important explanatory factor (after the effects of baseline level of caregiving effort and group membership are accounted for) is the factor representing change in physical functioning. As the need for help increases, caregiving networks respond with increased levels of involvement. This finding does not hold for comparison group members in the New York City sample. For those sample members, there is no relationship between changes in need for help and the involvement of the caregiving network. Once again, without making too strong of a statement regarding program impact, it does appear possible that the New York City Home Care Program functioned to help caregivers respond appropriately to changing needs of frail elders.

In San Diego and among New York City program participants, three of the four factors contribute to explaining change in level of caregiving effort. In San Diego, the socio-emotional factor did not significantly contribute in light of the other measures. In this sample there is a clear distinction between between social contact and caregiving contact.

Table 5.5A

Analysis of Covariance Results for Change in Level of Caregiving Effort: New York City Treatment and Comparison Groups

	Treatment Group (n = 222)					Comparison Group (n = 72)			
	Beta	R^2 Change	Cummulative R^2	F of the Change		Beta	R^2 Change	Cummulative R^2	F of the Change
Covariate (1)					Covariate (1)				
Baseline Level of Caregiving Effort	.580	.337	.337	111.602***	Baseline Level of Caregiving Effort	.552	.304	.304	30.598***
Factors (2)					Factors (2)				
Physical Impairment	.332	.102	.439	39.960***	Caregiving Extensity+	.406	.145	.449	18.155***
Caregiving Burden	.153	.023	.462	9.342**	Caregiving Burden	.241	.053	.502	7.217**
Caregiving Extensity+	.160	.024	.494	10.246**					

* $p \leq .05$
** $p \leq .01$
*** $p \leq .001$

Once caregivers responded to increased needs, change in morale among sample members was not a relevant factor in the provision of care. For New York City program participants and comparison group members, changes in cognitive functioning were statistically unimportant to the provision of care once other factors were considered. The second and third explanatory factors in San Diego and among New York City program participants were the change in extensiveness of the helping system and change in caregiving burden. In San Diego, burden is relatively more important in explaining provision of care than extensiveness of the system, while among New York City program participants, the two factors make almost equivalent contributions; change in extensiveness of the helping network is slightly more important than change in helping network burden.

Among New York City comparison group members, once the baseline level of caregiving effort is accounted for, only two measures are observed to account for changes in caregiving involvement: extensiveness of the caregiving network and caregiving burden. Increments in caregiving involvement were associated with extending the range of types of helpers and increased burden in the system. Changing functional needs of clients do not appear to be relevant to level of caregiving effort in this group. The two caregiving system measures (extensiveness and burden) make large contributions to variance in level of caregiving effort and explain even more of the total variance than the three measures in the treatment group.

In all the equations, the direction of effects is that increased amounts of burden are associated with increased involvement in providing care. And, rather than the same amount of involvement being shared among a larger number of helpers, in both samples more help was being provided by a larger network. It can be argued that rather than burden being causal in explaining the intensity of caregiving involvement in a network, caregiving burden depends on the degree of involvement. As the literature suggests, it may only be at very high levels of burden that one could expect to observe a negative effect on the provision of care.

The ability of the factors to add to the explanation of level of caregiving effort at one year (after accounting for the initial level of involvement) varies for the San Diego and New York City samples. Once the initial level of caregiving and group membership are accounted for, the San Diego model accounts for only an additional eight per cent of the variance in caregiving. The regression model for the New York City treatment group is somewhat better, accounting for an additional 16 per cent of the variance in caregiving. For the New York City comparison group, the two significant factors (caregiving network extensiveness and caregiving burden) account for almost an additional 20 per cent of the variance in caregiving involvement at one year. The regression models for the New York City samples may have been more successful in part because there was more residual variance in caregiving level of effort available for the other measures to explain. The baseline measure of caregiving effort <u>uniquely</u> accounted for only 18.5% of the variance in caregiving effort at one year among the treatment group and 11.4% among the comparison group. Unreliability of the level of caregiving effort measure may largely account for the relatively small amount of variance in the year one measure accounted for by the baseline measure. In contrast, the baseline measure in San Diego uniquely accounted for 39.4% of the variance in level of caregiving effort. If that measure is more prone to error, the degree and direction of error appear to be fairly consistant.

The unique contributions of factors which follow in the regression equations are smaller in San Diego than in New York City and ultimately account for a lesser proportion of variance.

ELABORATION OF FINDINGS

Analysis now turns to the question of the types of sample members for whom the general findings hold in each sample. Demographic measures reported in Chapter IV as being related to informal level of caregiving effort were ethnicity or race (white or non-white), sex, marital status (married or unmarried), and living arrangement (alone or not alone). The question is, are there subpopulations within each sample for whom the observed conditions and the relative importance of conditions to caregiving varies. Does knowledge of these characteristics add to our ability to explain change in level of caregiving effort. Finding that being white or non-white or male or female adds significantly to the variance in level of caregiving effort, over and above the variance explained by the regression model, indicates that the model works differently based on these characteristics. A non-significant contribution indicates that the regression model derived applies equally to each subgroup. Prior to concluding that a characteristic is meaningful to caregiving change, interactive effects between demographic characteristics and the general conditions or factors are tested for significance. Results of analyses are presented in Tables 5.6A through 5.6C.

In San Diego, none of the demographic characteristics contributed significantly to the regression model indicating that the factors apply in the same way to all types of frail elders in this sample. Sample members are homogeneous with respect to how physical impairment, burden, network extensiveness and participation in the project functioned to

Table 5.6A

Analysis of Covariance Results for Applicability of Model to Sample Subgroups

San Diego

Variable Set Added[a]	R^2 Change	F of the Change	Beta
(1) Baseline Level of Caregiving Effort Group Membership Physical Cognitive Functioning Caregiving Extensity+ Caregiving Burden	.575	91.117***	
(2) Ethnicity	.001	.588	-.028
(3) Interaction Terms: Ethnicity X Physical-Cognitive Ethnicity X Burden Ethnicity X Extensity Ethnicity X Group	.004	.971	
(2) Sex	.001	.512	-.027
(3) Interaction Terms: Sex X Physical-Cognitive Sex X Burden Sex X Extensity Sex X Group	.005	.950	
(2) Marital Status	.004	2.978	.069
(3) Interaction Terms: Marital X Physical-Cognitive Marital X Burden Marital X Extensity Marital X Group	.007	1.378	
(2) Living Arrangement	.003	2.659	.067
(3) Interaction Terms: Living Arrangement X Physical-Cognitive Living Arrangement X Burden Living Arrangement X Extensity Living Arrangement X Group	.007	1.315	

[a] See Figure 3.2 for coding

* $p \leq .05$

** $p \leq .01$

*** $p \leq .001$

Table 5.6B

Analysis of Covariance Results for Applicability of Regression Model to Sample Subgroups

New York City Treatment Group

Variable Set Added	R^2 Change	F of the Change	Beta
(1) Baseline Level of Caregiving Effort Physical Functioning Caregiving Burden+ Caregiving Extensity+	.486	51.345***	
(2) Ethnicity	.002	.975	-.050
(3) Interaction Terms: Ethnicity X Physical Impairment Ethnicity X Burden Ethnicity X Extensity	.004	.528	
(2) Sex	.004	1.583	-.062
(3) Interaction Terms: Sex X Physical Impairment Sex X Burden Sex X Extensity	.002	.264	
(2) Marital Status	.011	4.821*	.117
(3) Interaction Terms: Marital X Physical Impairment Marital X Burden Marital X Extensity	.002	.221	
(2) Living Arrangement	.022	9.505**	.168
(3) Interaction Terms: Living Arrangement X Physical Impairment Living Arrangement X Burden Living Arrangement X Extensity	.006	.911	

[a] See Figure 3.2 for coding

* $p \leq .05$

** $p \leq .01$

*** $p \leq .001$

Table 5.6C

Analysis of Covariance Results for Applicability of Regression Model to Sample Subgroups

New York City Comparison Group

Variable Set Added	R^2 Change	F of the Change	Beta
(1) Baseline Level of Caregiving Effort Caregiving Burden+ Caregiving Extensity+	.502	22.845***	
(2) Ethnicity	.011	1.473	.106
(3) Interaction Terms: Ethnicity X Burden Ethnicity X Extensity	.031	1.442	
(2) Sex	.016	2.217	-.129
(3) Interaction Terms: Sex X Burden Sex X Extensity	.038	1.822	
(2) Marital Status	.001	.081	-.025
(3) Interaction Terms: Marital X Burden Marital X Extensity	.028	1.282	
(2) Living Arrangement	.000	.000	.000
(3) Interaction Terms: Living Arrangement X Burden Living Arrangement X Extensity	.030	1.357	

[a] See Figure 3.2 for coding

* $p \leq .05$

** $p \leq .01$

*** $p \leq .001$

enhance or diminish the provision of informal support.

It has already been observed that group membership affects which factors explain caregiving involvement in the New York City sample. The affect of demographic characteristics are examined separately for the treatment (Table 5.6B) and comparison groups (Table 5.6C). The New York City comparison group sample can be considered homogeneous with respect to factors which enhance or diminish the provision of informal support. Similar explanatory relationships are observed for the four demographic factors studied. Among treatment group members however, marital status appears to moderate the effects of explanatory factors on caregiving involvement. Over and above the effects of the explanatory factors, married program participants appear to be receiving more help than unmarried participants. (Since there is no interaction between extensiveness of the network and marital status and since spouses are typically primary caregivers, it is likely that increased efforts are coming from the spouse).

SUMMARY

This chapter began by describing the selection of measures representing constructs suggested by theory and empirical research to enhance or diminish the provision of informal social support. These constructs are physical functioning, self-perceived health, mental-emotional functioning, social resources, caregiving structure, caregiving burden, and participation in a special program of community oriented case-managed services. Analysis revealed that each of the samples experienced change over time in these areas as well as in the frequency or amount of informal social support. In seeking a more parsimonious set of factors or conditions relevant to the provision of social support, differences between the two samples emerged. Frail elders in the two samples could not be described by exactly the same constructs though certain similarities did exist. Of theoretical interest is the finding that some typical social constructs may lose their relevance under certain conditions. For example, among very severely impaired frail elders requiring extensive caregiving, the meaning of social contacts dissipates as a discrete construct probably because social contacts become indistinct from caregiving contacts.

Participation in the community-based long-term care program was associated with some changes experienced by sample members. In New York City, treatment group members were more likely to retain their functional levels while comparison group members were more likely to improve their functioning; comparison group members were more likely to maintain or increase the burden among helping network members while burden decreased for treatment group members. In San Diego a possible relationship existed between group membership and changes in socio-emotional functioning.

The relative importance of conditions or circumstances to the provision of social support was evaluated after accounting for initial caregiving involvement and for the affects of group membership. Comparison group membership was associated with increased caregiving involvement in San Diego while treatment group membership was associated with increased caregiving involvement in New York City. The analysis revealed that the affect of the key factors was not the same for treatment as for comparison group members in New York City and analyses were conducted separately for these two groups.

For the San Diego sample, changes in socio-emotional functioning did not add to the ability to explain caregiving involvement; for the New York City sample, changes in cognitive functioning were not relevant. Of the factors that were significant, changes in physical impairment were far and away the most important factor in explaining changes in the provision of social support for the San Diego sample and New York City treatment group members. There was no relationship between changes in physical functioning and the provision of care for New York City comparison group members.

Among less severely impaired elders who primarily need help with tasks such as shopping, cleaning and transportation, the number of limitations reported for all the helpers in the network is relatively more important than the extensiveness of the network, and participation in a community based program was likely to be associated with a decrease in the provision of informal support. Among very severely impaired program participants who not only need help with tasks such as shopping and cleaning but who also require almost daily help with tasks such as dressing and bathing, extensiveness of the helping network and burden in the system were almost equivalent in their relationship to caregiving involvement, and participation in the program was associated with increased caregiving. For the relatively more impaired sample who did not receive special program services, increased extensiveness of the helping network was more important to explaining caregiving involvement than were the number of limitations experienced by that system.

It was also observed that among the more severely impaired, whatever changes transpired in functioning and in the helping network, married frail elders received more help than their unmarried counterparts.

Reasons for differences in the relative importance of the caregiving burden and extensiveness factors are not obvious. Consider again the composition of the respective helping networks of the samples presented in Chapter IV (see Table 4.6). Though differences aren't great, San Diego sample members rely to a greater extent on friends and neighbors compared to New York City sample members. It is possible that without the history and strong bonds found among families that the burdens or limitations of caregiving become more salient in explaining the provision of help. It is also possible that the more moderately impaired San Diego was approaching the point where more levels of the caregiving network need to be activated.

Participation in the community-oriented program of services appeared to enhance the ability of the helping network to provide support in the most impaired sample, but apparently inhibited informal support in the less impaired sample. It is possible that program case managers in New York City were able to elicit more help for their married clients. Spouses may have the greatest vested interest in trying to provide as much care as possible so as to not lose the services of the program and to keep their spouses at home. It may also be that under conditions of severe impairment and extensive caregiving involvement, embeddedness in the spousal role and the easy availability of help appears to extract added help regardless of changes in impairment, the helping system or burden experienced. Even with the aid of case management, it is possible that spouses of severely impaired elders are providing care in response to aspects of the situation other than the ostensible needs of the older recipient. Among the more moderately impaired, case management may have functioned to help caregivers provide care in response to the need for help.

NOTES

[1] Though the focus here is on utilizing change to understand relationships, it is noted that even without change in any particular independent variable, important questions could be pursued. In particular, it is possible for the relationship between any independent measure and level of caregiving effort to be greater (or lesser) for sample members who participated in the program in contrast to those who did not. The interpretation would then be made that the program was working in some unobservable way (e.g., it did not affect functioning, burden or social resources) to affect the ability of caregivers to provide care. However, the interest of this study is how the program might have affected those factors established as potentially affecting caregiving involvement. The affect of program participation will be addressed later in this chapter.

[2] Where one year measures have data missing, mean scores were substituted in subsequent analysis.

[3] Lost variance is more of a concern where the focus of study is on prediction. Despite capturing less than 100% of the variance among these measures, covariation of the study measures should be retained and it is this covariation which is central to this effort.

[4] Differences in the two samples existed for measures of functional impairment and for some demographic measures. One sample was more impaired than the other, and one sample contained a larger proportion of non-white sample members. These differences should not affect the basic relationships among social constructs. Differences in quantity of these measures should not substantially affect the quality of relationships among measures, though strength of relationships might vary.

[5] All variables contribute to the formation of each factor to some degree. However, the variables which load most heavily on one factor are used to describe the essence of the underlying construct.

[6] Because there are differences between the treatment and comparison group, caution should be exercised in interpreting these relationships as indicators of the impact of the program.

[7] With the forward entry method, variables are entered into the equation one at a time. Variables already in the equation will not be removed as they might be with the stepwise method.

VI. CONCLUSION

This chapter begins with a review of the study findings and then proceeds to elaborate these findings in two ways: in terms of their theoretical meaning and in terms of their meaning for public policy and programs. The chapter ends with suggestions for further research.

SUMMARY OF FINDINGS

Using the framework provided by the construct of social support, the question examined in this dissertation was, under what conditions and circumstances is the provision of social support enhanced and under what conditions and circumstances is provision inhibited. The study examined the provision of instrumental social support to frail community-residing elders who were treatment and comparison group participants in two community-based long-term care demonstration programs funded by HCFA in the early 1980's. The impact of the programs on informal support in three sites (South Carolina, San Diego, and New York City) was included as part of the evaluation of the impact of these demonstration programs on health care utilization and costs. The San Diego and New York City programs had the most complete data sets and were used for this analysis.

Theoretical literature and empirical research suggested salutary (e.g., increasing need for help) and inhibitory factors (e.g., burden and the provision of an organized program of formal services) germane to the continuing provision of social support. These constructs were analyzed multivariately in order to assess which factors were more or less important in explaining the provision of support.

Many aspects of social support are of theoretical and empirical interest, for example, the changing structure or composition of networks, the burdens experienced by primary caregivers, and the qualitative aspects of caregiving relationships. For this study, instrumental social support was operationalized as level of caregiving effort, a construct with theoretical as well as policy relevance. The construct was defined in different ways in the two samples: as an interval level measure of discrete episodes of help from two helpers in various tasks necessary for daily living (amount of help), and as a ordinal level measure of frequency of help from two helpers in various tasks. All data were available at two points in time, one year apart. All sample members were continually impaired and received at least some informal help during the year.

The analytic approach addressed two major methodological challenges: studying change over time and assessing the relative importance of different but related conditions and circumstances to the provision of social support. The study analyzed deviational change among independent and dependent variables; used factor analysis to identify underlying global constructs which were unrelated to each other; and, finally, used study samples and measures which varied somewhat from each other as a replicative strategy. The value of the virtual replication strategy was manifested as the study progressed, discerning conditions which limited the generalization of a single model and furthering an understanding of the phenomenon.

While both study samples represent the elderly population designated as frail, the samples differed from each other in ways which had important implications for subsequent analyses. One sample was clearly more physically impaired in activities of daily living, the ability to perform personal and self-care. The other sample was less physically impaired and had an unusually large proportion of members with moderate to severe levels of cognitive impairment.

In each sample, the study found that at baseline, more social support is provided to those who are more physically, mentally, and emotionally impaired; to those who have more social resources and available sources of help; to those who are married, male, have higher incomes, and possibly who are non-white. The greater the extensiveness of the caregiving network (more helpers of varying relationships), and the more burden in that caregiving network, the more help is being provided.

Factor analysis was implemented to discern the underlying structure of the set of information and to derive factors which were uncorrelated with each other. Four major factors were derived in each study sample. In each sample, physical impairment is the most important construct describing the set. While different measures are linked with the core concepts of caregiver burden and caregiving network extensiveness, caregiving burden and caregiving extensiveness are clearly distinct from each other. Differences in factor structure are attributed largely to the differences between the sample in physical and cognitive functioning which are sufficient to result in different relationships among social constructs. In the moderately impaired sample, socio-emotional functioning is a discrete and meaningful construct; in the severely impaired sample, aspects of social functioning are intermixed with caregiving extensiveness and caregiving burden. Severity may also explain the differential order of factors which were derived -- in the more impaired sample, extensiveness of the helping system is superordinate to the burden experienced in that system. Other differences (e.g., the linkage of cognitive and physical impairment in one but not the other sample) are attributed to the inclusion in the San Diego sample of a substantial number of moderately to severely cognitively impaired sample members.

Participation in the program appears to have had a different affect on caregiving depending on the site: in San Diego the mean level of caregiving involvement decreased for program participants while in New York City, the mean level of caregiving involvement increased for program participants. Program participation for more severely impaired elders (the New York City sample) also appears to have affected physical functioning and caregiving burden: the average level of functioning was retained and the average degree of burden decreased for program participants relative to the comparison group which improved in functioning and which experienced increased burden. Because New York City treatment group members were more severely impaired relative to the comparison group to begin with, these changes cannot categorically be attributed to the program.

Each multivariate regression analysis began by removing variance associated with level of caregiving effort at one year which was due to the initial level of caregiving effort and to participation in the study as a treatment or comparison group member. The analysis proceeded to evaluate the relative contributions of the four derived global constructs: physical impairment, caregiving network extensiveness, caregiving network burden, and socio-emotional functioning in San Diego, and cognitive functioning in New York City, as well as the differential effects of these constructs for members of the treatment and comparison groups. Once a final regression model was derived, the applicability of the formulations to frail elders with different characteristics (married or unmarried, living alone or with others, white or non-white, and male or female) was assessed.

Slightly but not completely different conditions leading to the provision of social support are identified for each study sample. For the more severely impaired participants of the New York City demonstration program and for the sample members in San Diego, change in physical impairment is an overriding enhancer of support provision. For severely impaired New York City comparison group members, instrumental support is provided apparently without regard to the changing need for help. For this group of frail elders, the conditions leading to more support are an increased range of helpers and more burden in the helping network. (The possible reciprocal effects of caregiving involvement and burden will be discussed below).

In the San Diego sample and among New York City program participants, extensiveness of the helping network and burden (in that order) are positively associated with provision of support. It does not appear that adding helpers to the system necessarily reduces the burden in that system (though it may reduce the burden or limitations perceived by any particular helper) and in fact may introduce added limitations. In these samples, added burden and limits do not act to inhibit the provision of support.

The relationships between explanatory factors and social support provision apply to the moderately impaired sample in general. On the other hand, findings for the severely impaired sample suggested that a single set of conditions is not similarly applicable for all sample members. Marital status is observed to affect the provision of care for the severely impaired program participants in the New York City sample. Married sample members increased their level of support beyond that which changes in need would seem to require.

THEORETICAL IMPLICATIONS

This study has produced findings of theoretical interest in terms of social support provision as well as in terms of social constructs.

In general, the study of social support has focused on the relationship of support to health and other outcomes of importance. Fewer efforts have been directed toward explaining the provision of social support itself. The findings presented here contribute knowledge in this important area.

For the most part, the importance of physical impairment as a driving force in the provision of instrumental social support was unmistakable. Caregivers by and large increase and decrease their helping efforts as the needs of frail elders change except under certain conditions. First, responsiveness to changing needs was not evident among moderately impaired frail elders who did not have the benefit of case management and among married severely impaired frail elders who did have the benefit of case management. The demonstration programs of services and case management may have functioned differently for different subpopulations of frail elders. Or, it may be that the programs themselves had different qualities and that the type of frail elder was not the determinant of the finding. These effects will be discussed below. Second, as the literature suggested, at least under certain conditions (severe impairment), social role embeddedness may override the importance of physical impairment in explaining support provision. Without knowing more about the nature of the arrangements and quality of these relationships it would be unreasonable to conclude that "unnecessary" help is being provided. And, even were "unnecessary" help being provided, no value can be placed on that provision. The nature of helping may be a component of a long-standing set of role relationships, and/or it can be dependency inducing.

The role of cognitive functioning in social support provision in this study is unclear. Under conditions of moderate physical impairment, cognitive functioning was not distinct from physical functioning and together the two types of impairment were strongly related to provision of support. However, the moderately impaired sample may be somewhat unusual in that a higher than expected proportion of members had moderate to severe cognitive deficits. Caution must be exercised regarding any conclusion about the effect of cognitive changes on support. Where impairment is more severe, and where cognitive and physical functioning were distinct constructs, changes in cognitive functioning were not relevant in the model of social support when considered along with changes such as physical impairment. While cognitive impairment by itself is associated with provision of support, in the company of other factors, the measure of cognitive impairment used in this study does not appear to be significant in explaining change in support provision. Aspects of cognitive and psychological functioning which may be most difficult to deal with, for example, disruptive behavior and wandering, were not included in the data sets.

The roles which caregiving burden and caregiving extensiveness play in explaining support varied. The relative importance of these constructs may vary depending on the extent to which friends and neighbors are relied upon compared to family members. Where friends and neighbors are more prevalent, burden may play a larger role; where family are more prevalent, extensiveness may be relatively more important. Conclusions about these constructs are made difficult by the ambiguous nature of the factor analysis results. The construct of caregiving system extensiveness, having helpers of different types of relationships, does not appear to be particularly compelling. In each sample, other variables were linked to the idea.

The provision of social support, at less than extreme degrees of burden, is possibly more likely to result in caregiving burden than vice versa. Burden probably needs to be quite severe before it would act as an inhibitor of social support. The levels of burden experienced by members of the caregiving networks studied here were not high enough to test the hypothesis. It is also possible that the relationship between burden and provision of care may be more relevant to the study of individual caregivers than to caregiving networks. In this study, caregiving involvement was examined among a network of caregivers, the composition of which may have changed over time. The effects of burden on a particular helper may have been more relevant to social support than burden of all caregivers. Even if one person in a caregiving network became overburdened to the point of no longer helping, it is likely (though unknown in this study) that a replacement helper or helpers was found.

Study findings also suggest that the relevance of the familiar concept of social resources or network diminishes under conditions where intensive caregiving is occurring. It is possible that social contacts become predominantly characterized as caregiving contacts. The suggestion does not imply that the contacts are not edifying in terms of emotional support but that at least in situations of severe physical impairment, some of the meanings typically comprising interpersonal relationships may become dissociated.

Another relevant factor for which the study could not control are the different geographical locations of the two programs. Though the exact nature of the locations are not known, there are general distinct aspects of locale which might influence the results. The influence of locale cannot be easily disentangled from differences in frailty level. San Diego is known as a retirement community to which many older people relocate. Such relocation may bring greater reliance on non-family members for help. Friends and neighbors could more easily be displaced by formal service providers. In contrast, in New York City, elders by and large have grown old and frail in place. Family may be more available, and enduring ethnic neighborhoods can be a source of continuing aid.

In an attempt to address to what degree severity level is the key factor versus particular site, more severely impaired members from the San Diego sample (who might be more like most of the New York City sample), and less severely impaired members from the New York City sample (who might be more like most of the San Diego sample) were selected for further analysis. Findings are discussed with great caution -- the factor structure could be dissimilar from the original samples. Bivariate relationships between group membership and the factors were somewhat more similar in the two sites. In the San Diego severe analysis, group membership was positive and not significant (a negative trend was observed for the original New York City sample); physical impairment continued to be most important followed only by caregiving burden. In the New York City moderate analysis, like the original San Diego findings, group membership makes a positive and significant contribution. Changes in cognitive impairment now take precedence in explanatory power (more help was provided to those who retained or improved their cognitive functioning) followed by caregiving burden and extensiveness of the system as in the original San Diego analysis. To the extent that cognitive impairment defined the San Diego impairment factor, it might be concluded that the prominence of the the cognitive impairment factor for moderately impaired New York City sample members mimicked the San Diego findings. However, the direction of effect if opposite.

For "severes" (the New York City sample and the subset of more severely impaired San Diego sample members), group membership was related in opposite ways to caregiving in the two sites. Treatment group members in San Diego appear to be receiving less informal help while treatment group members in New York City appear to be receiving more informal help. For "moderates" (the San Diego sample and the subset of less severely impaired New York City sample members), program participants at each site appear to be receiving less informal help.

The findings suggest that any organized program of community-based long-term care service which includes active case management may inhibit helping efforts by caregivers of less than severely impaired elders. In part, the nature of the tasks with which these two types of impaired populations need help probably influences whether or not caregivers increase or decrease their efforts. Instrumental tasks can be done by anyone and most frail elders would willingly accept help from a non-intimate for tasks like housecleaning or shopping. But, for severely impaired elders who must be helped in and out of bed, with getting dressed, or bathing, intimacy may be preferred (despite the often onerous nature of the tasks). Furthermore, once functioning has diminished to very low levels, help from multiple sources, formal and informal, is likely to be required in order to maintain the person at home. There is simply no option for significantly reducing one's involvement other than institutionalization, and that is an option that is not commonly used.

However, frailty level is not the only factor that may be operating. Among the severely impaired, how an organized program of services and case management operates may determine whether informal caregivers increase or decrease their efforts.

POLICY IMPLICATIONS

Long-term care service provision to older persons (both in and out of institutional settings) is a major public and personal concern due to escalating health care costs and the growing demand for services. The growing number of older people, especially the very oldest of the old, suggests that the need for continued caregiving will become more widespread and more crucial both to individuals and to the public health care budget. Demonstration programs funded by federal and state governments have been evaluated for their ability to provide necessary long-term care services and case management to the frail elderly and reduce expensive institutional care, all without increasing the overall cost of care. To the extent that formal services substitute for services which would have been provided by informal supports, community-based programs lose their ability to be cost efficient. Thus, it has become increasingly clear that these community-based programs must be built upon the foundation of the informal support system.

The evidence presented here reinforces the importance of targeting services to certain segments of the frail elderly population, of the importance of case management and service limits in retaining and even enhancing the provision of care by the informal support system. Targeting programs to less than severely impaired frail elders who do not need personal care on a daily basis increases the likelihood of substitution of formal for informal care. For those who are moderately impaired and do not need extensive personal care, formal aid for instrumental tasks is more likely to be sufficient and informal caregivers can more easily become superfluous. In the case of personal care tasks, the nature of the tasks mean that formal care by itself would rarely be sufficient -- other sources of aid will likely be required as well. It is in this latter case that despite ongoing care, community programs may reduce caregiving burden in the system.

Though the South Carolina sample was not able to be subjected to this analysis, it is possible that the severity level of their sample members (even more impaired than New York City) in part explains the retention of informal assistance described in Chapter II. The extreme severity may even suggest that increments in informal care were not possible whereas in New York City, while impairment was severe, there was still room for caregivers to increase their efforts. Programmatically, it also appears that in working with sample members and their helpers, the New York City program and the San Diego program were able to help caregivers increase or decrease their caregiving efforts based on need for help. Clearly, the supply of instrumental social support can be responsive to need for the service on the part of the older person. To the extent possible, medical and rehabilitation efforts should be included in community based programs.

These findings imply that more severely impaired elders will retain their caregivers out of necessity. Part of that necessity may be caps or limitations on formal service provision. Of the three projects in which informal caregiving was evaluated in the National Evaluation of Community-Oriented Long-Term Care Projects, the two with neutral (South Carolina) to positive (New York City) impacts on informal care also had caps or limitations on the services which would be provided. In the case of South Carolina, the cap was in the form of a limit on the amount of money which could be used for each case. In New York City, continuing clients could require no more than 20 hours of formal home care per week. In each case, if informal providers were not retained, clients would be threatened with the loss of project services. Service caps were not used in San Diego.

It is also important to realize that demands on caregivers of severely impaired elders who participate in community-based long term care may become even greater and that extra services may be required. One common finding of the evaluation of long-term care program impact on service utilization was a decrease in the number of nursing home days used by program participants. These members were being cared for at home by informal caregivers with the help of formal services. In some ways, informal caregivers could be confronted with even more difficult caregiving situations.

Results of this study in combination with other literature suggest four key policy goals for cost-effective provision of community long-term care services:

- target services to the severely impaired;

- o address functional and rehabilitation needs of frail elders;
- o cap service provision; and,
- o provide case management which addresses caregiver needs.

FURTHER RESEARCH

The research implemented for this dissertation did not examine every possible condition and situation which can effect social support. Nor did it examine the myriad other aspects of social support and caregiving relationships, especially the more subjective aspects of care. Results of the research presented do raise issues which could be successfully explored.

Two issues of measurement need to be addressed. First, the study relied on secondary information about caregiver burden and limitations. Further research might examine the relation of burden to support with first-hand information on burden, that is from caregivers themselves. Second, restriction of range on measures, especially level of caregiving and burden, limits the strength of relationships observed. Inquiries which can improve upon the level of caregiving effort indicator should be sought. For example, in the current evaluation funded by HCFA of the Social Health Maintenance Demonstration Projects, assessors obtain estimates of hours per week that help is provided. Validity and reliability of level of caregiving effort measures should be pursued. With the data at hand it would be possible to try and predict sample members who experienced significant reductions and increments in caregiving involvement. If the measures are valid, the same variables should be related to caregiving involvement in each sample.

The present study examined help provided by a changing network of helpers; it did not focus on a primary source of help. Additional research could determine the effect on the primary caregiver of changes in the helping network. Additional research could also focus on provision of social support among caregiving networks with varying compositions especially those which involve friends and neighbors in contrast to family members.

"Restriction of range" may also have been a limiting factor of the research in a number of ways. In order for certain kinds of data to have been available and used in the study, New York City Home Care clients were assessed as still fitting within the service limits. Therefore, anyone whose caregivers were no longer able to provide sufficient care would probably not have been retained. Research studies which obtain data prior to significant caregiving change (e.g., upon institutionalization) are designed to mitigate this problem. Caregiving and independent measures were examined at two points in time one year apart, perhaps too short of a time period for the influence of factors to be fully felt. Studying two discrete time points does not address the experience of caregiving nor how formal services worked with families over time. Formal services were examined by use of a proxy measure, participation in the special program. Varying intensity of service provision by the program may have influenced caregiving involvement.

The issue of the role of cognitive impairment in the provision of support merits further investigation. It is possible that the behavioral manifestations of impairment rather than merely the severity of disorientation to person, place, and time would be most relevant. And, different conditions may pertain to provision of personal care aid in contrast to help with instrumental aid.

Finally, the study took it's starting point the policy concern that the services of informal caregivers be retained or enhanced in order to meet the needs of a growing older population. While economically necessary in some respects, many researchers are addressing the costs of caregiving to caregivers and their families, whether it be lost income or services to other family members. And, it cannot blithely be assumed that caregiving may never exact it's toll on frail elders as well. There are skills and temperment required for extensive nursing care, and whether publicly providing services is cost effective or not may really beg the issue of the desirability and coming necessity of supporting informal caregivers.

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